

Final Report on Focus Groups

Statewide Family Assessment of
Medicaid Managed Care:
2001 HealthChoice Focus Group
Project

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EXECUTIVE SUMMARY

The 2001 HealthChoice focus group project was conducted to support the overall evaluation of Maryland's HealthChoice program. The project involved a series of seventeen focus groups, conducted throughout the state, with parents and primary caregivers of HealthChoice-enrolled children. The purpose of these focus groups was threefold: to gain insight into client's perceptions of the MCO system; to better understand the problems that parents encounter in navigating this system and in obtaining needed care for their children; and to better understand parents' perception of the quality of care their children receive under HealthChoice. In addition, the project also sought to determine whether parent and caregiver perceptions and experiences differed by race, income level, geographic region, and child health status.

It is important to keep in mind that the nature and strength of focus group research is to elucidate and explore problems in a given area, in this case problems experienced by children in HealthChoice. As such, the goal of each focus group discussion was mainly to reveal, probe and explore parents' negative experiences with the HealthChoice program. While the majority of participants reported many positive experiences, most of which are noted in this report, the primary focus of the focus groups-- and of this report -- centers on exploring and understanding the problems that parents and children have encountered with HealthChoice.

Overall, parents hold HealthChoice in high regard. Findings from the focus groups illustrate this clearly. These positive aspects are outlined below:

- **Most parents are satisfied with HealthChoice and the care their children receive through the program.** Parents give high marks to their child's primary care provider and praise the quality of health care and comprehensive coverage HealthChoice provides. Parents feel their children are well cared for in the program. Parents of children enrolled in the Maryland Children's Health Program (MCHP) and parents without previous Medicaid experience are especially pleased with the quality of the HealthChoice program.
- **A key factor in how satisfied parents are with HealthChoice is their relationship with their child's primary care provider.** The parents who are most pleased are those who feel their child's primary care doctor provides high-quality care, takes a personal interest in their child's health, and is accessible – keeping the lines of communication open. Parents who have this kind of relationship with their child's doctor – which most parents in this study do – feel their child receives higher quality care than those with a less established relationship with a provider. For many parents, satisfaction with HealthChoice appears to be closely tied to their ability to retain their primary care provider of choice. Indeed, most

parents say the reason they chose their current MCO is to keep their child's doctor.

- **Most parents are pleased with HealthChoice's eligibility determination, enrollment and renewal processes.** This is especially true of parents signing up for HealthChoice via MCHP, who say they have an easier time with eligibility determination than those signing up through the Department of Social Services (DSS). Parents enrolling for HealthChoice through DSS have additional paperwork to complete if they are applying for other government assistance programs at the same time. For some, DSS is perceived as stressful and inefficient- a source of frustration most parents prefer to avoid.
- **The majority of parents are pleased with their child's prescription drug coverage.** They say most of the medications their children need are covered. However, some wish the coverage was extended to include everyday items like over-the-counter pain and allergy medications. Others wish they were not limited to using certain pharmacies that may be farther from their home.
- **Parents whose children were once uninsured are most appreciative of HealthChoice.** Parents in these focus groups have experience with a variety of insurance arrangements, including periods in which their children were uninsured, privately insured, and insured in Medicaid before HealthChoice. Parents whose children were once uninsured are particularly grateful for the HealthChoice program and convey a sense of relief about no longer having to worry about paying for their child's care.

Despite parents' high regard for the program, there are specific areas that parents feel HealthChoice could improve upon. These areas are outlined below:

- **Parents are confused about the health care system in general, and HealthChoice in particular.** Most parents are confused by the relationship of HealthChoice, MCHP and Medicaid. Many are unclear how HealthChoice interacts with their MCO and their doctor's office. They tend to identify with their child's doctor, not these other entities. In fact, interaction with HealthChoice is limited for most parents, largely because their main point of contact with the health care system is through their doctor's office and not their MCO.
- **While selecting, enrolling, and changing MCOs is a relatively pain-free process for most parents, a few perceive the changes in participating plans to be overwhelming.** Most parents feel comfortable selecting and enrolling in their MCO of choice. However, this process is complicated by the changes in plans that participate in HealthChoice and having to keep track of those MCOs in which their doctor's office or clinic actually participates.

- **Many parents perceive specialty referrals as an unnecessary step and a bureaucratic hurdle.** Like consumers in private managed care plans, HealthChoice enrollees complain about referrals. Most parents consider referrals to be a “hassle” and do not recognize their potential benefit (i.e., that their child’s care is being managed by their primary care provider (PCP)). Most problematic, however, are the long waits parents say they endure before their child can actually see the specialist – many say it can take months to get an appointment.
- **At least a few parents in each group have experienced billing problems, often because of unauthorized emergency room visits.** Most parents believe HealthChoice does or should cover all emergency room visits and are surprised and frustrated when they receive bills from the hospital. These focus groups suggest that some parents are unsure about their plan’s ER policy, hence parents may receive bills because they do not obtain authorization from their provider or plan for the ER visit or because they take their child to the ER for non-emergency visits.
- **Some parents experience problems when calling member services and hotline numbers.** When parents have problems with their health care that their provider cannot resolve, some call a 1-800 number on the back of their plan’s card. Most however are unclear who they are actually calling, and are frustrated by the experience. Many of these parents complain of long waits on hold, confusing automated response systems, uninformed member services representatives, lack of follow-up by staff, and staff’s inability to resolve their problems in a timely manner.
- **Parents complain about the shortage of doctors – both primary care providers and specialists – in clinic and in personal practice settings.** Although most parents complain about the shortage of doctors in their geographic area, this shortage is particularly acute in rural areas. Two issues appear to be causing this shortage, according to parents: 1) doctors are dropping out of their health plans; and 2) fewer doctors are participating in HealthChoice plans than previously. Some parents suggest the main reason for the shortage is their perception that it is no longer cost effective for doctors to deal with certain health plans. In other words, some parents feel many doctors are not getting paid enough by the insurance companies to continue to offer health services to their patients.
- **Parents feel the dental and vision benefits offered by HealthChoice are inadequate.** Most parents complain there are too few dentists accepting their MCO and that many dental providers refuse to accept new patients. Parents also say the list of participating dentists constantly changes, making it hard to find a regular dentist. Dental coverage is perceived as too limited, as services like orthodontics are usually not covered. Likewise, many also feel their vision coverage is lacking, mainly

because only poor quality and unattractive eyeglass frames are available to their children through the program.

- **Despite their awareness of the importance of preventive care, most parents do not appear to be using preventive care services *regularly*.** Parents acknowledge the importance of preventative care, but many still do not regularly obtain preventative care services for their children. Like many other parents, it appears that their contact with the health system occurs mainly when their child is sick or injured. Furthermore, few parents perceive either HealthChoice or their MCO as actively promoting preventive care for children (although, one or two MCOs were singled out as ones that do send out preventive care notices). If parents do receive notices about check-ups or other preventive services, most believe they come from their child's pediatrician or dentist.
- **Some parents report being treated poorly by staff at clinics and doctor's offices.** Some parents feel receptionists and front-desk staff are rude to them because they have public insurance. A few also say personnel – including both doctors and nurses – have treated them poorly. Some parents feel there is a strong sense of stigma due to their insurance status. Many believe they are treated as inferior and receive lower quality of care because of this. Feelings of stigma were voiced by both African-American and Caucasian parents of all income levels and in all regions .
- **While parents who were uninsured were pleased with having coverage, parents who have experience with employer-sponsored insurance are divided over which insurance situation is preferable.** Some parents are grateful to no longer have to bear the burden of paying for private insurance – namely, the co-pays and deductibles, as well as emergency room visits and prescription drugs. In contrast, parents who paid little or nothing for their child's care under their employer's plan feel less positively toward HealthChoice because, they say, the treatment they received while privately insured was superior and more personal.
- **Many parents had experience with Medicaid before the current MCO-based system.** For the most part, these parents prefer the old days of the “red and white cards.” The main reason they preferred the old system: they enjoyed a wider choice of providers – from doctors to emergency rooms to clinics to pharmacies. According to these parents, the old system was less of a hassle; referrals were not required, and it was generally easier to navigate. Others say “everything was paid for” under the old system. However, a vocal minority of parents insists the new system has more advantages. They appreciate the support and coordination MCOs provide; essentially, they embrace the idea of “managed” care. Others appreciate that managed care generally means having a regular doctor, which translates into more personal treatment and greater privacy.

- **Few parents know about all the services HealthChoice offers, including case management, classes, newsletters and other informational materials.** Parents whose children were enrolled in Medicaid prior to the inception of HealthChoice, in particular, fail to recognize that these services are a bonus, something they were not offered under the old system. It is not so much that parents do not appreciate the provision of these services – because the handful that utilize them are grateful – but that most parents are simply unaware that these services exist at all.
- **For the most part, parents are more similar than dissimilar in their perceptions and experiences in HealthChoice.** Little difference in opinion exists across lines of race, income level, child health status or child age according to our findings. Perhaps the most important factor determining parents' attitudes and experiences is geography: rural parents express different concerns, particularly in terms of access to providers, when compared to parents living in urban and suburban settings.

Please refer to the full report to see more detail about these and other focus group findings.

INTRODUCTION

The Maryland Department of Health and Mental Hygiene commissioned Buffalo Qualitative Research (BQR) and Lake Snell Perry & Associates (LSPA) to conduct focus groups for the *Statewide Family Assessment of Medicaid Managed Care: 2001 HealthChoice Focus Group Project*. This project was funded by a grant from the David and Lucile Packard Foundation.

The goal of the project has been to support the overall evaluation of the HealthChoice program – Maryland’s statewide program for providing managed health care coverage for low-income families -- and to gain new insight into how HealthChoice is performing for children, who constitute three quarters of the program’s enrollees.

Through this project, the Department sought to learn about families’ experiences with, perceptions of, and concerns about HealthChoice. Specifically, these focus groups explored families’ perceptions of the MCO system, the way in which families interact with managed care systems and processes, families’ problems and issues in accessing needed care – particularly preventive care – and families’ perceptions of the quality of care. The results of this focus group project are intended to assist the state in developing effective strategies to improve access to care and delivery of services within the HealthChoice MCO system – ultimately improving HealthChoice so that enrolled children and their families are better served.

It is important to keep in mind that the purpose of these focus groups was to understand problems that children in HealthChoice have experienced. The goal of each of the two-hour focus group discussions with parents of HealthChoice enrolled children was to probe, explore and elucidate negative experiences with the program. While the majority of focus group participants had many positive comments and experiences with the program, which are noted in this report, the primary focus of the groups and of this report centers on the problems that people have encountered with HealthChoice.

The study, which included seventeen focus groups with parents or guardians of children enrolled in HealthChoice, was also designed to discover whether perceptions and experiences differed along lines of race, income level (as indicated by Medicaid eligibility category), geographic location, and health status of the children. Four mini pilot groups were held on August 7th and 8th, 2001, to test the focus group discussion guide and to learn how parents discuss the HealthChoice program. In addition, the pilot groups allowed the Department to refine the targeting; for example, a decision was made after the pilot groups to add another group of “sicker” children in a rural area.) The results of the pilot groups are captured in an interim report entitled, *Pilot Report on Focus Groups, September 26, 2001*.

BQR/LSPA conducted thirteen focus groups, between October 2nd and 25th, 2001, which are the main focus of this report. The sites for the focus groups and the parents invited to participate were chosen to reflect the diversity of Maryland's HealthChoice population. The RFP specified that at least one of the focus groups had to be conducted in each of the state's six regions: Baltimore City, Suburban Baltimore and Annapolis, Suburban Washington, Western Maryland, Southern Maryland, and the Eastern Shore. Beyond that, groups were distributed geographically in terms of the target groups' population density. This distribution plan allowed us to incorporate voices from all parts of the state, including rural areas, while concentrating our efforts in urban centers and suburban areas where more HealthChoice families reside. In rural areas, we selected locations that were not the most populous in that region in order to maximize our opportunity to learn about access problems.

In addition, because HealthChoice serves both Medicaid families as well as families in MCHP, who have slightly higher incomes, we thought the study would benefit from hearing the perspectives of both groups. It was important to see whether and how these two populations' experiences with and assessments of the HealthChoice program differed. Therefore, roughly a third of the groups were held with MCHP parents, a third with Medicaid, and a third mixed MCHP and Medicaid parents.

Lastly, the racial distribution of the groups was designed to reflect the racial make-up of the HealthChoice population. According to state records, 59 percent of HealthChoice enrollees are African American and 29 percent are Caucasian. We did not include the remaining 12 percent of the HealthChoice population in these focus groups because of language issues.

Table One outlines the composition of the groups in more detail.

Table One: Organization of the Focus Groups¹

Group	Date/Time	Group Description				
		MCHP or Medicaid	Race	Residents of:	Location of Group	# of Participants
Pilot 1	8.7.01 4:00 p.m.	Medicaid	African-American	Baltimore City	Downtown Baltimore	6
Pilot 2	8.7.01 6:30 p.m.	MCHP	African-American	Baltimore City	Downtown Baltimore	7
Pilot 3	8.8.01 4:00 p.m.	Medicaid	White	Baltimore City	Downtown Baltimore	4
Pilot 4	8.8.01 6:30 p.m.	MCHP	White	Baltimore County	Downtown Baltimore	2
1	10.2.01 4:00 p.m.	Medicaid	African-American	Baltimore City	Downtown Baltimore	9
2	10.2.01 6:30 p.m.	MCHP	African-American	Baltimore City	Downtown Baltimore	9
3	10.17.01 4:00 p.m.	MCHP & Medicaid Sick Children	African-American	Baltimore City	Downtown Baltimore	7
4	10.17.01 6:30 p.m.	MCHP & Medicaid Children Under 1	Mixed Race	Baltimore City	Downtown Baltimore	8
5	10.11.01 4:00 p.m.	MCHP & Medicaid	Caucasian	Baltimore Suburbs	Baltimore Suburbs	11
6	10.11.01 6:30 p.m.	MCHP & Medicaid Sick Children	African-American	Baltimore Suburbs	Baltimore Suburbs	8
7	10.15.01 4:00 p.m.	Medicaid	African-American	PG/MC Suburbs	Washington, DC	8
8	10.15.01 6:30 p.m.	MCHP	African-American	PG/MC Suburbs	Washington, DC	10
9	10.22.01 4:00 p.m.	MCHP & Medicaid Sick Children	African-American	Western MD	Cumberland, MD	10
10	10.10.01 4:00 p.m.	Medicaid	African-American	Southern MD	LaPlata, MD	7
11	10.10.01 6:30 p.m.	MCHP	Caucasian	Southern MD	LaPlata, MD	7
12	10.25.01 4:00 p.m.	MCHP	Caucasian	Eastern Shore	Cambridge, MD	7
13	10.25.01 6:30 p.m.	Medicaid & MCHP	Caucasian	Eastern Shore	Cambridge, MD	7

Organization of the Report

The report opens with a brief overview of contextual details including participants' top-of-mind concerns and concerns about their children's health. The section that follows reviews what parents identify as the strengths and weaknesses of the HealthChoice program. Specifically, we discuss parents' interactions with the administrative side of HealthChoice, their MCO, and their actual health care providers, as well as parents' opinions about breadth of health care coverage and the quality of the care their children receive.

Subsequent sections discuss findings about preventive care in the HealthChoice system, issues of stigma and personal treatment, and parents' perceptions of HealthChoice, respectively. Finally, the last section explores parent's experiences

¹ Pilot Group 4 was scheduled to include four to seven participants, but only one of the scheduled participants attended. An interview was conducted with the intended participant and her husband.

with and feelings about health insurance generally, and public health insurance programs specifically. This section also addresses parents' thoughts about HealthChoice relative to other forms of insurance they may have experienced, including Medicaid prior to the inception of HealthChoice. Also included in this analysis is a section listing what participants feel are the best ideas for improving the HealthChoice system overall. The report concludes with a summary of the major perceptual differences among program sub-populations based on the following breakdowns – Medicaid eligibility category (income level), race, health status and age of child, and geography.

Lastly, an appendix is attached to the report, which includes the focus group guideline, and Handouts One and Two – exercises used in the focus groups.

METHODOLOGY

Development of Research Moderator's Guide

The focus group research moderator's guide was developed by BQR and LSPA in direct consultation with a DHMH inter-office team from the offices of Planning Development and Finance, Health Services, Operations and Eligibility, as well as the Deputy Secretary's office.

Selection and Recruitment of Participants for the Focus Groups

Focus group participants were recruited using lists of HealthChoice enrollees prepared by the Office of Planning Development and Finance (OPDF), Data Management and Analysis Division. All recruitment efforts were conducted by telephone using experienced professional recruiters. Each recruitment list included 500 randomly selected households (with phone numbers) from the universe of enrolled children living within a reasonable geographic distance from the focus group site who also met the specific eligibility, enrollment, age, race and health status criteria for the particular group. For all of the groups, only households with children who were continuously enrolled in HealthChoice for a year or more were considered.

Only caregivers of HealthChoice enrolled children were recruited for participation in the focus groups. In a few cases, grandparents and siblings attended the focus groups, having been assigned official custodial roles. However, regardless of their relationship to the child, this report refers to each participant as a "parent" in the main text that follows.

The six lower-income Medicaid groups consisted of caregivers of children aged one through sixteen living in families with incomes roughly below 100 to 133 percent of the Federal Poverty Level (FPL). The six MCHP groups consisted of caregivers of children aged one through sixteen living in families with annual incomes roughly between 100 and 200 percent of the FPL. In the three groups with children in poor health, DHMH used the "Adjusted Clinical Group™ (ACG)" case-mix risk adjuster to select children who were less likely to be healthy. For the single group consisting of mothers of children under one year of age, OPDF staff selected only children whose mothers had been enrolled in HealthChoice themselves for all or part of their pregnancy.²

For each of the seventeen groups, recruiters ensured that the group contained a mix of participants from various areas within the particular region and whose children were enrolled in different MCOs. Additionally, for the groups with caregivers of children in poor health, the recruiters ensured that that groups

² The Department decided to conduct this group because of recent concerns that Maryland's advocacy community raised regarding access to care for newborns.

consisted of participants whose children suffered from a variety of different medical conditions ranging from psychosocial (e.g., ADHD, depression) to chronic incurable (e.g., diabetes, severe asthma) to anatomical (e.g., cerebral palsy, bone disorders).

FINDINGS IN DETAIL

I. Context

In analyzing the focus group findings, it is important to understand the current mindset of the participants in the research study. It is also helpful to keep in mind parents' immediate concerns, worries and problems in order to understand where health care fits into their lives. These concerns include their economic and social situations, health problems, general concerns about their children and, perhaps more importantly, their general views toward health care. The following section offers a brief glimpse into the lives of families enrolled in HealthChoice.

General Concerns

Parents feel their children's lives are relatively trouble-free but they do share some concerns. Aside from universal worries and overall stress caused by the events of "9/11," financial concerns are paramount for most parents in these groups. Paying the bills each month is a top concern for parents. Single parents, students, and unemployed parents report difficulty making ends meet as they attempt to juggle home, jobs, school and family. One parent from Baltimore remarks, "I work, I go to school and it's very trying for me right now. So I find it hard because I'm a full time student and I work full time. I'm trying to stay active in their lives with their schoolwork, both of them are in school, and I find it hard."

I'm stressed, too, because I just got laid off, so I'm unemployed. And I still have bills. And Christmas is coming.

Parent, Baltimore
Suburbs

Parents in Western Maryland are especially concerned about the recent downturn in the economy as they lament the loss of jobs and factories in their community. One parent explains, "There are no jobs in this area that actually pay enough for our family to survive." Another parent agrees, saying, "Our children need better; my oldest daughter is in college and I tell her, 'Please move.'" Meanwhile, the types of jobs that remain available, according to some parents, simply do not pay enough to survive. A fellow parent agrees, asking, "Who wants their child to go into Wal-Mart and work for Wal-Mart for the rest of their life?"

Parents living in urban areas raise some safety concerns. They say they cannot afford to live in better neighborhoods because of their low income, and believe the poorer neighborhoods they must live in are unsafe. In the words of One parent in Prince George's/Montgomery County, 'Housing is up to the roof. You can get housing if you want to live in a drug-infested place. A lot of people just say, 'Well I live within my house. I don't live outdoors. Whatever goes on out there stays out there.' But you still have to walk out. It's [just] not the right environment.'

Some parents also worry about a lack of morals and discipline among children, particularly the grandmothers in the focus groups. One grandmother living in Southern Maryland says, “I’d say, because I have teenagers, it’s the moral climate out there that worries me a lot. Just raising them and having them be good people. Because there’s a lot of stuff out there that’s not good.”

Concerns about Their Children’s Health

Above and beyond the general concerns stated above, most parents insist their biggest worry is their children, and many are quick to cite specific health issues as their primary concern. This concern is not uniform, however. Many parents in the later Baltimore city groups³ – both Medicaid and MCHP enrollees -- as well as parents in the Prince George’s/Montgomery County lower income Medicaid group have few complaints or concerns about their children’s health. Some in the MCHP (This stands for Maryland Children’s Health Program – the State’s name for its S-CHIP program) group state that their kids were feeling “great.”

Asthma and allergies are the most common ailments plaguing many children across groups. In addition, a handful of parents discuss their children’s diabetes, eczema and seizures. Often, more than one child in a family has a medical condition like this parent on the Eastern Shore, “One of my 16 year olds has asthma but she does pretty good. She uses an inhaler. My four year old has to be medicated every day. He takes two different kinds of medications, plus an inhaler and a nebulizer. He has asthma.” On the more severe end of the spectrum, ailments include sickle cell disease and one child with celiac disease (a gluten intolerance problem). Several parents in the Baltimore Medicaid/MCHP groups had children who suffered from issues relating to their bones, like hip rotation problems.

I'm laughing because our children share the same illness...My son has asthma, severe allergies and eczema. It seems like maybe in the last year and a half or so it's gotten chronic. It's gotten a lot worse. And my daughter has minor allergies.

Parent, Prince George's/Montgomery County

Behavioral problems, although limited to a smaller number of children, are still noteworthy and include anxiety and conduct disorders, such as ADD or ADHD, and one child who suffers from bipolar manic depression. In the words of one parent in Baltimore, “Both of my children have been diagnosed with ADD... When they were in elementary school, they told me they would have problems... as they grew older they had learning disabilities. Both of them are on medication and my son is getting worse. My main concern about my son is, when is it ever going to end or *is* it ever going to end?”

Regardless of whether the diagnosis is physical or psychological, many of these children require constant care, including testing, medical equipment (most prominently inhalers and nebulizers for asthmatics) and regular medications. One Prince George’s/Montgomery County mother attests to this

³ Groups 1 and 2 in particular. See Table on page 10.

need for constant attention and care: ‘My son who's 11 is diabetic...I have to monitor him...He's still at the point where his blood sugar is fluctuating...He takes insulin four times a day.’

Notably, parents in Western Maryland point to bronchitis, pneumonia and other cold-related ailments that are a primary cause of concern during winter months. “Winter will be the worst, because that's when their ear infections set in,” One parent observes, continuing, “That's when they get their sinus infections. Sinus infections are the biggest thing for our family.”

How Parents Heard about HealthChoice

Parents heard about HealthChoice through a variety of sources. The most common source is the Department of Social Services (DSS), not surprising given the relatively high level of experience these parents have with other social service programs in addition to HealthChoice, followed by suggestions from doctors, nurses or other medical personnel. Familiarity with the Department of Social Services (“the system”) seems to play an important role in facilitating enrollment itself, as well as awareness and knowledge overall of the enrollment process. Other parents say they first heard about HealthChoice on the radio or in TV ads. Several heard about the program through information sent home from their child’s school, and a few parents found program pamphlets at their local library.

I was watching television one day, and they said 1-800 KIDS NEED for health insurance. So I called them, they got all my information, and my son got a card within about two [or] three weeks. And he was right back in the program.

Parent, Baltimore

Notably, pregnant women were more often than not approached at their clinic, hospital, doctor’s office or prenatal classes. ‘I attended Northwestern High School. At the time I was pregnant, they had a teen parenting class in that school and they were the ones who told the parents where to go and what to get,’ says a parent in Prince George’s/Montgomery County. A parent from Southern Maryland also received support after her baby was born, saying, “I got mine at the hospital. When my daughter was born, they knew I didn’t have insurance and they told me about it and where to go.”

Confusion about HealthChoice

In an attempt to ascertain how participants feel about HealthChoice versus the old Maryland Access to Care and Fee-For-Service Medicaid programs, participants were asked if they knew the difference between HealthChoice MCOs, Medical Assistance and MCHP. It quickly became apparent that the distinctions between these entities lack any true meaning to most parents. For example, parents are unsure what HealthChoice is and how it interacts with and relates to Medicaid (which many parents call Medical Assistance), MCHP, their MCO, and their individual doctors’ offices or clinics. Likewise, many parents, including some who have children enrolled in MCHP, seem equally confused about what MCHP is and how it differs from Medicaid.

Medicaid is a program all parents have heard of, and many can give details about it. Most parents quickly say that this is the program where the “state pays,” or when medical services are free. On the other hand, parents are noticeably less familiar with HealthChoice. When asked to define HealthChoice, most parents could only abstractly define the program. In fact, most parents responded with more questions of their own, not answers. Since this confusion first became evident in the pilot groups, the discussion guide was changed to concentrate more on parents’ experiences with their MCO and their doctor or clinic, and included fewer questions specifically about HealthChoice.

It's the same, Medical Assistance, HMO, HealthChoice, whatever. It's all the same.

Parent, Baltimore Suburbs

Despite their confusion about what HealthChoice is and how it interacts with MCHP and Medicaid, participants have much to say about the merits and shortcomings of the HealthChoice/MCO-based system. The remainder of this report examines the positives and negatives of the system in terms of administrative aspects like enrolling and selecting plans to the coverage and the quality of the care itself.

II. Rating HealthChoice

Most parents rate HealthChoice highly. They give high marks to their child’s doctor, praise the quality of health care their children receive, and have positive comments for the breadth of coverage provided. MCHP parents and parents without prior Medicaid experience seem especially pleased with the program.

HealthChoice is working well for most parents. Many use the words “content” and “satisfied” to describe their overall feelings about the program. One parent living in the Baltimore suburbs says, “I don’t really have much of a complaint about it... I’m getting a lot of services so I really can’t complain.” This view is shared by the majority of parents. Another parent in Baltimore agrees, stating, “It covers the majority of my needs.” The breadth of coverage provided by HealthChoice is recognized and appreciated by most parents.

I feel that it is easy. That for me the biggest relief is that things are covered and I don't have to worry about that and I think that the people who work with my son's program [are helpful]. I think they really kind of look out for [you]-- if I call and have a problem, they do help me.

Parent, Baltimore Suburbs

The primary feeling that parents express toward the program in the focus groups is gratitude. In the words of one parent in Baltimore, “There are many times that I wanted to quit my job because I couldn’t afford the bills...I am grateful that this insurance does exist. I need it. It helps me out a lot.” Parents across focus groups share similar expressions of relief at having found a solution to their health care woes. One parent living in the Baltimore suburbs, who explained that she has custody of her sister, tells how she worried about not qualifying for the program. “I was just very ecstatic that they accepted me,” she recalls, continuing, “And it was just a strange situation where her father just dropped her off the insurance and didn’t help [her out]. So, I had to find

something quick. And in order to get her on my husband's, we had to adopt her. And the courts look funny on adopting a sister. So, I was glad that they had accepted her."

For the most part, parents say they enrolled in HealthChoice with few expectations and so were pleasantly surprised by the program. "I really didn't know [what to expect] because I didn't have any insurance," admits one parent living in Baltimore, while a parent in Western Maryland agrees: [You] couldn't have any [expectations]. You were thankful for what you got." Meanwhile, those who said they came to the program with low expectations agreed it was because they thought it would be a typical government program offering free services. "I thought it was going to be awful," one parent from Southern Maryland recalls continuing, "I thought that since it was like the state was paying for it, I thought I was—it was really going to be hard. But I've found it to be really helpful. Very helpful." For some, much of their satisfaction and praise comes from a feeling that they did not have a choice in the first place. "I am very pleased with it because it could have been worse. I might not have qualified for anything. So my children are getting care," reveals a parent living in Baltimore.

Despite these high levels of satisfaction and parents' overall appreciation of the program, they believe the program can be improved. The remainder of this report discusses specific aspects of HealthChoice in further detail.

A. Administrative Aspects

Parents give mixed reviews to the administrative aspects of their children's health care. Most give high marks to the eligibility determination, enrollment and renewal process, as well as choosing their MCOs – each of which they say are fairly straightforward administrative processes. In contrast, referrals and billing issues are a proverbial thorn for most parents. Many also are confused about where to turn for help, and are unclear about the process for resolving problems within the HealthChoice system. Lastly, it appears that most parents are unaware that HealthChoice provides transportation services. Each of these administrative processes is explained in greater detail below.

Eligibility Determination and Renewal (Re-enrolling)

Feedback from parents about the eligibility determination and renewal process is overwhelmingly positive. Many parents say both processes are quick and easy. This is an important insight – national studies tend to identify the eligibility determination process for Medicaid, in particular, as a barrier to enrollment because of difficult applications, burdensome paperwork requirements, and the time-consuming application process. This does not appear to be the case in Maryland.

One parent describes eligibility determination as “a piece of cake.” Those who applied through the mail recall a very simple process. Most parents believe the forms are straightforward. One parent from Baltimore describes them as “cut and dry.” Few parents said they needed help with the eligibility determination or renewal process, and a handful of parents received assistance from their child’s school or their own human resources person, which was beneficial.

[Enrolling was] Very easy...I called. I asked a few questions...I proceeded with my personal information and I had my application within three days...and my son had insurance in 30 [days].

Parent, Baltimore

Many parents who applied through the DSS, however, experienced some difficulty and frustration. This is strikingly evident among some parents in the Baltimore City focus groups, and to a lesser extent among a few parents in both the Western and Southern Maryland groups. Parents in Baltimore City recall applying at DSS as time-consuming – “sitting and waiting” is a common complaint – with a lot of paperwork asking a lot of unnecessary and intrusive questions. Regardless of race or income level, parents there agree that applying at DSS is a “hassle.” Furthermore, lower income Medicaid parents in Southern Maryland prefer applying at the Department of Health as opposed to the Department of Social Services because there is reportedly less waiting, less paperwork, and less overall hassle. “[The] Health Department [was] real quick. Quick and easy — it ain’t Social Service,” one parent recalls. Furthermore, another parent recalls when her sister went to the Department of Social Services and an employee referred her to the Health Department instead. “[Be]cause she said it’s much easier if you go through the Health Department and it was,” she reflects.

For those parents applying at the DSS, where parents are often simultaneously applying for other programs in addition to Medicaid, paperwork is perceived to be relatively harder to complete and more burdensome. The questions asked are more offensive and intrusive, say many parents who applied at the DSS. One parent from the Baltimore suburbs who enrolled through the DSS says, “I just don’t like the fact that they want to be in your business. They want to know everything. They want to know every source of income you’ve got. Everything.” A fellow parent in Western Maryland agrees: “They’re nosy. I mean, truly. They want to know everything.” The additional and intrusive questions parents site are required for programs other than Medicaid but parents are not always aware of this.

A few parents also share stories of ill treatment from DSS workers at the time of application. “The Department of Social Services is rude. They are condescending to you. It’s not right,” believes one parent in Western Maryland. In contrast, applying through DSS does not appear to be a controversial issue among the majority of parents in the Baltimore suburbs, Prince George’s/Montgomery County or Dorchester and surrounding counties on the lower Eastern Shore.

Choosing an MCO and a Doctor

Most participants find the process of choosing and enrolling in an MCO fairly easy. While several parents had the program assign them a plan, the majority of parents chose their own MCO. Some parents made this choice based on location. One parent in Baltimore recalls, “Some locations were better than others. But they won’t take different HMOs of HealthChoice.” Others say coverage was critical to their choice – specifically hospital visits, prescription drugs, medical supplies, vision and dental care. Says one parent living in the Baltimore Suburbs, “I went by what they insured. Because of my diabetic child, I had to have certain supplies and be able to see certain doctors without limit because she had to see an endocrinologist and all that. She had to have her blood worked on two times a month. A lot of insurance will not let you do that.” Like this one, a few other parents also say they investigated their MCO to ensure certain specialists were available to them.

My children’s pediatrician accepted MCO B and that’s why I chose MCO B.

Parent, Baltimore Suburbs

However, the primary criteria in choosing a MCO, was keeping their child’s pediatrician. One parent in Prince George’s/Montgomery County chose her plan for this reason. “I didn’t want to get rid of [my child’s doctor] because he’s been there ever since I moved out here in 1992,” she reasoned. Many parents also voice the importance of the child-doctor relationship as being an extremely important factor. One parent in Southern Maryland says she chose her MCO mainly because of the doctor, “Because the kids went to the doctor and they liked him.”

For most parents, the actual process of choosing and enrolling in an MCO is straightforward and few complain about this task. Many parents review the booklets from various MCOs together with the provider directory in search of their pediatrician of choice. Others ask for advice and recommendations on the best MCO from their pediatrician’s office, family members or friends. “The receptionist was like, ‘This is the best one.’ So I picked it,” recalls one parent in Baltimore.

As for the enrollment packets sent by the MCOs, while some parents recall having been sent one, just as many claim they did not, or cannot remember receiving one upon enrollment. Those parents that say they received one are once again divided: some recall being overwhelmed by the overall length and failed to read it, claiming it was “too big”; others found it very useful and found themselves referring to it repeatedly in their search for providers and convenient locations.

Adding a level of confusion to the memory of many parents is the fact that they receive two separate packets – one from HealthChoice, which is mailed by the enrollment broker once they are deemed eligible for the program, and one from their MCO, after they have enrolled in one of the six plans.

Generally, most of the parents who say they received either or both packets, took them seriously, like this parent in Baltimore who made good use of the charts and graphs in the HealthChoice provider directory. “HealthChoice sends you a big manual, a thick text. It has all the MCOs listed...it gives you different graphs, what’s covered from X-rays to anesthesia to hospitalization, dental, eyewear,” she explains. Most parents who received a packet from their MCO, however, used it more like this parent in Baltimore, who says, ‘Not completely and fully and in detail but I looked at the index and picked some things I thought were beneficial to me and scanned through that.’” Regardless of the extent to which they utilized either packet, these parents were almost all aware of what they contain, namely, a large directory listing providers for the state of Maryland, including, optometrists and dentists, as well as a list of drugstores and important phone numbers.

Notably, parents in both Southern Maryland and the Eastern Shore raise an important concern about the provider directories: many of the lists contain outdated information such as providers that no longer participate in the selected plans. . “We got a little book with information and a provider list, which when you started calling 90 percent of what was in the book, it didn’t exist. It didn’t even take that plan,” recalls one parent on the Eastern Shore. Another parent in that same group concurs: “A lot of them are way off and the ones that are around here were either not taking new patients or they just got out of the system because they didn’t want to fool with it.”

With the exception of those in rural areas, most parents enjoy a reasonably smooth process when initially choosing an MCO. What appears to cause some parents frustration are the numerous transitions that HealthChoice has recently undergone. Owing to the pullout of the state’s largest MCO, Freestate, as well as enrollment closures in several counties for other MCOs, parents have had to scramble to enroll in other plans. In some cases, this makes choosing an MCO an ongoing process for parents. On top of this, several PCPs (primary care physicians) have ceased to participate in the program leaving parents unhappy with the MCO and PCP selection available to them. Illustrating this point, one parent describes preparing for her MCO to move out of the Eastern Shore: “They sent me letter saying Freestate is getting ready to leave the area and this is the number you need to call and so I called that number and they gave me a list of doctors, I believe, ... we actually chose [MCO D]...I think that they gave me a list of doctors and I had to call them to see if they were taking new patients and what insurances they would take,” she recalls. The majority of parents are familiar, albeit disgruntled, with the process of having to accommodate such changes in the health care system.

Parents describe how they chose a doctor for their child. Aside from continuity – as mentioned earlier, most parents place a premium on remaining with their existing providers -- location was also a large factor. As one parent in Prince George’s/Montgomery County explains, ‘I didn’t even have a doctor at the time. I picked the plan and then I was fortunate enough to find a doctor

four or five blocks from my home.” Another parent looked in the phone book for doctors close to home, and then asked around from her own doctors for advice. Other parents received advice from friends or from a doctor or nurse in their hospital.

Eastern Shore parents say they have no choice nor any list of eligible doctors from which to choose. “There is only one in the area,” says one parent. Parents in Western Maryland complain of the same problem. In addition to “the two doctors they have listed” many feel they are not taking any new patients. This is especially difficult for those parents whose children suffer from more serious ailments and require constant care from specialists. This quickly becomes a burden because most do not have the luxury of being able to drive 45 minutes or an hour for a doctor’s appointment. The following quote from this parent in Western Maryland highlights the sense of helplessness and frustration many rural parents feel toward their plans:

I got so frustrated [when I had the Freestate plan] because at that time it said that there were like eight or ten doctors in Cumberland and LaVale and Frostburg’s surrounding areas who took the card and I called and not one of them did. So I had to then call the 800 number...it was terrible, it really was, trying to find a doctor... My old doctor stopped taking it and then I had to pick another doctor. So I called every doctor around and I found one that took the plan.

Switching MCOs and Doctors

At least one parent in each focus group reports having switched MCOs at some point in time. These parents say the primary reason parents choose to switch MCOs is to remain with their child’s primary care provider. Often this involves following their primary care providers as they leave MCOs. Many parents will not hesitate to change plans if their doctors do. “I had my son at the time when they changed the hospital over to [MCO E]. The secretary I knew for 12 years told me, ‘Hey, we’re switching over,’ and wanted to know if I could switch over. I wanted to switch over because I have a good pediatrician,” insists one parent in Prince George’s/Montgomery County.

**Long as Dr. ____
stays there, my
children stay there.
If she leaves, then
they leave.**

Parent, Baltimore

While most parents who switched MCOs say it is a fairly simple process, some do encounter problems. A few parents claim that despite having made the switch, they are still billed because the new plan failed to properly register them. One parent in Baltimore says she tried to get her daughter in for her eye doctor appointment weeks after switching, only to be told by the doctor’s office that she was “invalid.”

Some parents also disagree with some of the rules concerning switching MCOs – mainly, the one-year lock-in or “waiting” period, as most parents refer to it⁴. Some parents say they have to wait three or four months, others

⁴ In general, once an enrollee has selected an MCO, the enrollee must remain with that plan for one year. However, enrollees are permitted to change MCOs at any time if their situation meets

insist one full year is required before switching. In the words of one parent in Prince George's/Montgomery County, "I tried [switching] but I had to deal with the waiting period. I had to wait until six months or some time." Others do not believe they have to wait at all. One parent in Southern Maryland adds, "The only time you don't have to wait is if you have a newborn baby, up to three months."

A few parents spoke of switching pediatricians, either because their child reached the age of 13, after which many pediatricians will no longer keep them as patients – a problem many parents in Western Maryland report – or because they no longer liked that particular doctor or they had complaints about the service. For the most part, parents who had switched doctors say it was a fairly easy process – except those on the Eastern Shore who agree it was difficult. "That's a nightmare...Because you can't find anybody that's taking new patients or that you don't have to go 300 miles to see. That's no joke. I'm not exaggerating. A lot of them are really far off," says one parent there.

Referrals

The administrative process that parents complain about most is referrals for specialists. Like their counterparts who are enrolled in commercial managed care plans, many HealthChoice parents are frustrated by having to obtain referrals and consider them an extra hassle. (Many parents also take issue with having to wait lengthy periods to see specialists, an issue that will be discussed in the next section.) Although few parents find referrals difficult to get when they need them – some have nurses and doctors that take care of it on the spot, (Parents say MCO B, MCO F, MCO A are good about this) many, nevertheless, see them as an unnecessary hurdle to quality health care. Often access to health care services becomes complicated; referrals don't reach specialists on time or authorization is wrongfully (according to parents) denied. A parent in Baltimore explains this problem below:

You need referrals mostly for everything. And then, some referrals are not authorized by the clinic. If the doctor says you need to go, you have to call the insurance people, and they have to OK it...it seems like no matter which [plan] the state of Maryland allows you to choose, it's always some kind of difficulty when it comes to your care....

Another problem with referrals that a few parents cite is that they can expire. Several parents were taken by surprise when learning this fact. One parent living in the Baltimore suburbs recalls, "I had a referral and it said I had two visits. I got to the doctor's office and found out that the referrals had expired in August. I didn't know it had an expiration date. When it said two visits I

one of the following conditions: transportation hardship (for example, the enrollee has moved and now lives quite far from his or her provider); dissatisfaction with auto-assignment; desire to keep all family members in the same MCO; and, under certain circumstances, when the enrollee's PCP is no longer participating in the enrollee's MCO.

thought it meant two more visits, but that meant before August and so they cancelled my [child's] appointment.” Another parent in Baltimore questions why referrals have to expire at all saying, “When I took [my daughter] to the eye doctor, to the specialist about her eye, the referral only lasts for six weeks. If they give her an eight-week appointment or seven-week appointment, and if I go back and don’t get the referral from the primary doctor, she can’t be seen. So, why can’t this referral last longer than six weeks?” This is a larger concern for parents in Southern Maryland, where specialists are harder to come by. “My problem is that the referrals are only for a certain period of time, and if you can’t—if you’re going to specialist, sometimes you can’t get the appointment within that 30 days. [Be]Cause most often that’s all it is, for 30 days and a lot of times you have to wait two months before you can get to a specialist,” says one parent.

While the majority of parents have firsthand experience with the referral process, a few have avoided many of these pitfalls. These parents say their plan – one mentions MCO D in particular – does not require referrals. One parent living in the Baltimore suburbs boasts: “The specialist that he had to go to doesn't require the referral. He just goes...It was an orthopedic specialist... And I don't have to go through his primary care physician. You just don't have to do that.”

Billing Issues

Many parents also complain about billing mistakes with HealthChoice. Often this occurs when they are billed for health care services that either should have been covered or they believe were supposed to be covered. The extent to which some of this confusion might be a result of ineligibility is unclear, as it was not fully explored in the groups, but this could easily be an important factor explaining parents’ perceptions about coverage. In any case, the result is that parents are caught in the middle between the MCO and the provider trying to resolve the mistake. As one mother in the Baltimore suburbs says, she had “bills coming from everywhere.”

In most cases, parents explain that the billing issue is a result of an emergency room visit for their child. Most parents believe their insurance should cover this cost at all times. However, parents explain that their MCO claims they did not receive prior authorization for the visit. Although parents are generally aware of their MCO’s emergency room policy, many parents are unclear what they did to incur the bill.

To a lesser extent, parents mention being wrongfully billed for other areas of service as well. It is important to note that most parents do not perceive they did anything wrong, and almost universally blame administrative error for why they received the bills.

Admittedly, parents are sometimes confused about their coverage. This parent in Southern Maryland explains a misunderstanding she had:

I've gotten some bills before – and I'm not sure if they didn't cover it or they wouldn't cover it or if it was a mistake. My older daughter's had several broken bones and a certain splint she had for her foot that the orthopedic [doctor] gave her, they sent it back several times. And then, one time, the company that we actually purchase it [the splint] from said that the insurance company wouldn't pay for it. I wrote the number on the bill again and sent it back and I haven't gotten it back again. So I don't know and I'm not sure if the insurance really doesn't pay for certain things, or not, but I haven't gotten it back yet.

They say they will take care of it. Then in a couple of weeks you get the same bill...It took them a while, a couple of months to get resolved.

Parent, Baltimore

The most common reaction to receiving bills is to “trash” them, or ignore them. In the words of one parent in Baltimore, “Every month I get that same bill and every month I drop it in the trash.” Many parents do not have the time, or the “tolerance” in the words of a few, to tackle the perceived bureaucracy in order to get to the root of their billing problems. In a few cases, ignoring the problem has led to collection agencies and poor credit ratings. For example, a parent on the Eastern Shore who was billed for an emergency room visit says, “I had to pay it off because it was just sitting on my credit and I'm trying to get my life straightened out. To get it off I had to pay it.”

Calling Hotlines, Resolving Problems and Seeking Help

Parents that try to resolve their problems over the phone say it is time-consuming, and they feel they are given the run-around. It seems to take significant effort on the part of many participants to resolve such problems. In the words of one parent living in the Baltimore suburbs:

I just went round and round and round with these people...With the state and [MCO F]. One would say she's on it [covered or eligible]. The other would say no they messed it up. The other said no she's on it everything's fine. The other one said use the red card. The other one said this...It was horrible.

These parents also point out the length of time it takes to work out these issues --Some waiting three to six months, others over a year. In fact, it reportedly took one mother 4 years to get reimbursed for some medical equipment for her child.

It is not clear among parents in the focus groups who they are even calling when they try to resolve problems. While parents are generally aware of the 1-800 numbers listed on their MCO cards, only a few participants in each group have experience with actually calling the hotlines. With one or two exceptions, those who have called the hotlines had trouble remembering which hotline they called. While most parents eventually resolve their problems, they assert that the process took too long and was a hassle.

It is also evident from these groups that while parents know they can call and often have more than one number at their disposal, they are unsure as to what the various numbers are for – 1-800 numbers, nurse’s hotline, MCO-action lines, enrollment broker, etc. The majority of calls made by parents are to resolve administrative issues having to do with eligibility, enrollment or billing issues. Some have called the enrollment broker (only one for entire state) instead of the 1-800 number because they failed to receive insurance cards; others called for help finding participating doctors or clinics. As stated earlier, a few parents have also called to get to the bottom of billing disputes, specifically over emergency room charges, like this parent in Cambridge, who says “I called the 800 number on the back of the card. I had to call for billing problems when my daughter had to go to the emergency room. It took me two months to get that straight to where they finally did pay it.”

Resolving emergency care issues, however, are often directed to the “nurse’s hotline.” The majority of parents are aware as well as appreciative of this particular option. “One time my son was sick and I couldn’t get hold of the doctor. So, I called the nurse line. I did everything she said, which I had already done in the first place. And then she gave me the okay to take him to the hospital,” recalls one relieved parent from the Baltimore suburbs. Most other parents have had similar positive experiences. They use terms like “helpful” and “I got good results.” Some parents are especially happy to know they can call that number after hours, once the clinics have closed.

Parents who have called one of the 1-800 numbers listed on the back of their card to resolve administrative disputes report mixed results. As discussed above, in most cases parents do not differentiate between their plan’s administrative help hotline and the HealthChoice Enrollee Action Line, hence it is not possible to determine which one they are calling. Many parents recall having to wait while being put on hold, often for many minutes, as a universal problem. Other parents say they only get through to voicemail, and sometimes their calls are not returned. A few parents in Western Maryland point out that the 9-5 options they have to call do not fit their own work schedule. A quote from this parent in Western Maryland exemplifies many of these frustrations:

When I finally got through, the girl was nice but she couldn't help me... She said ‘I can't do anything about this.’ She said, ‘Your time is expired.’ I said, ‘I just got this in the mail. How could that be?’ And she said ‘What's the postmark?’ And I told her and she said, ‘Well, here's the number you need to call.’ And then I called that number and couldn't get through because they close at five. And of course we work, so I'm still trying.

Parents in Cambridge are vocal about having to wait for service when calling a 1-800 number. The following dialogue transpired among three parents there: ‘Most of the time, when you call, you have to wait. They put you through to five or six different people and wait for an hour to talk to someone’, says one mother, followed by, “And they ask you to hold on for a minute and

you hear all this music. Then they never pick back up”, says another, and lastly, “Then finally after about an hour it disconnects on you. Then you have to start back over again,” adds yet another mother.

Transportation

Awareness is very low around the issue of transportation – most parents are unclear as to whether it is even covered through HealthChoice, while actual use is even less common. It is important to note that transportation services for HealthChoice enrollees are provided by local health departments – not MCOs. Moreover, these services must be medically necessary and authorized by the health department and an enrollee’s case manager or physician. When this mother in Western Maryland says, ‘I’ve never used transportation through the HMO, so I don’t really know,’ she is voicing the uncertainty of most of her fellow participants. Some parents argue that transportation it is limited to those with disabilities. Others believe a child has to be “crippled”, “near-death” or “severely disabled” in order to receive transportation. Furthermore, parents say they have never received information from their MCOs – or anyone else for that matter – about this service.

Only a couple of parents, MCO D recipients, spoke of having transportation services available to them through their MCO. ‘MCO D does. If you need to get you or your son or your child to the doctor, it’ll pay, it’ll send a car out for you,’ insists one parent living in the Baltimore suburbs. Another parent in that same group concurs: “It’s MCO D through Medical Assistance but MCO D will pay for you to go to a scheduled doctor’s appointment if your child is ill.”

Even fewer parents mention services provided by their clinics. Explains one parent in Western Maryland, “Usually over there at “[Physician Group Practice]” if you tell them you’re having a problem getting the kids there they will help you. They will find you someone to get you there that the card will help cover it.” While one other parents believes [Physician Group Practice] in Baltimore distributes vouchers for cab rides. But for the most part, parents are amazed when they learn transportation services are available at all.

B. Care and Coverage

Parents are generally satisfied with the care their children receive under the current system. Findings from the groups suggest that most parents appreciate the quality of care and breadth of coverage provided by HealthChoice. Parents use terms like “pleased”, “perfect” and “satisfied” to describe their feelings about their plans. Many parents share positive stories similar to this one, from a mother in Prince George’s/Montgomery County:

My child has received really good care. We even have behavioral problems where we had to go to the specialist. I had no problem.

Parent of a Child Under One, Baltimore

My daughter has a brittle bone disease but through [MCO E], where she's been going for 12 years, she's been going every time she needs to go...They're very good there. They always make sure they see her and take care of her. I go all the way to Baltimore, Maryland from Rockville to go to this hospital. I've been going there since I had all my children there and I won't go anywhere else.

In addition, most parents feel the primary care physicians their children see are competent and caring, and most seem to enjoy a high level of access to them. In fact, in groups where parents were asked to rate them on an alphabetical scale, most gave their child's primary care doctor an "A" and most other aspects of their child's care (be it dental, eye, or other) something considerably lower. As one parent in the Baltimore suburbs points out, "I was surprised about the better group of doctors. They give you a better grade of doctors." It is clear that parents place a premium on their relationship with their child's primary care provider; the extent to which they are able to retain their pediatrician of choice is therefore critical in determining not only their perceptions of their primary care provider, but their satisfaction with the program as well.

In addition to discussing doctors, the remainder of this section also highlights what parents see as strengths and weaknesses in the areas of emergency room, dental, and vision care, as well as prescription drug coverage, and some other areas of concern.

Perceptions of Their Primary Care Providers

The results of this study suggest that a key factor in satisfaction for most parents is their relationship with their child's primary care provider. Parents who have a particularly close relationship with certain doctors seem to feel their child gets especially good care. For example, two parents in Baltimore shared the same doctor, about whom they are very enthusiastic. As one of the two explains,

My kids go to _____ ... and they have Dr. _____ as their doctor. I love her but sometimes it's hard to get her. But the good thing with Dr. _____ is when they are infants or small she allows none of her sharing doctors [most likely residents or interns to] see them. She sees them and she's [the only one who sees them]....Dr. _____ is a good doctor and she follows through. One time I wasn't able to get to the clinic and she wanted to see my son so bad that she paid for me to take a cab. I was so taken with that gesture.

I've even had my doctor call afterwards and check up on him. I've never had that happen with doctors before her.

Parent, Southern Maryland

It is not surprising, therefore, that parents' satisfaction is also tied closely to their ability to retain their primary care provider of choice, usually one they have been using for a lengthy period if not since their child was born. As one parent in Baltimore explains, "I've had him since I had my first daughter. That's when he was a family doctor. All my nieces and nephews have been under this particular doctor." Another parent in Baltimore insists that should her child's doctor leave her plan, she would go with her. "I would go. If Dr.

_____ were to leave, I would follow her...wherever she goes... she's taken the time through the years and I've invested time in going to her, so I wouldn't stay. We wait hours on end just to see her."

Parents who are happy with their child's primary care provider are eager to share stories of their positive experiences. More often than not, they tell stories of doctors who go the extra step for their child, treat them with compassion, and keep them informed. "My daughter's pediatrician, she keeps me up to date with her shots, everything, bring her back such and such, she need to do this, she need to this," says one parent in Baltimore, which she appears to appreciate, while a parent in Western Maryland goes as far as to say, "I love my doctors...Yes, because I have older daughters. And "[Physician Group Practice]" has female doctors and my daughter is at that age where she doesn't want a male in the room with her."

Access to Doctors – Routine Preventive Care

Officially, preventive care is defined as care which includes well-child visits and immunizations, which children should receive on a regular, routine basis in order to maintain health and identify potential medical problems early. Parents were asked to comment on their ability to access routine preventive care (and later, about access to urgent care services) through their child's pediatrician.

Most parents report that they enjoy a high level of access to their child's doctor, for which they are grateful. The average wait is reportedly two weeks to one month for an annual visit, and parents seem content with this. Parents in clinic situations, like those in Baltimore City, point out that waiting time for an appointment also depends on whether they are open to seeing any doctor on rotation – which takes less time than waiting for a specific doctor. In the words of one parent in Baltimore, "Sometimes I choose to see my doctor—their pediatrician. If I want to see him specifically, it might take a month. But if I just want to go ahead and they can still get their physical or whatever with another doctor, here lately it's been a couple days out. I don't have to wait."

Having scheduled an appointment, parents can spend anywhere from "three minutes" to one hour waiting to be seen, with only a handful of parents in Baltimore city – among them a few parents with children under the age of one – recounting longer waits. Again, many parents seem resigned to the fact that a busier office often means longer waiting times and take it in stride, *including* some parents in clinic situations. "It depends if it's crowded, but here lately for the youngest two, they pretty much been in and out. The wait's been 30 minutes to get in the back," recalls one parent in Baltimore City. Many parents are also aware and resigned to the fact that their clinics and doctor's offices operate on an informal "first-come-first served" basis. Some Baltimore City parents recall having to wait for a long time when they brought in their

newborns for regular check-ups, but they too seem accepting of this situation. Says one parent there, “If the [child is] sick then they pay more attention to the sick ones then you know the ones just coming in just for like a check up or something.”

A few parents also appear pleased with the extended hours offered by their doctor’s offices, like this parent living in the Baltimore suburbs, who points out, “My husband doesn’t get off until 7:00. [My son’s] doctor’s office will close at 6:00. Now if my son needs to be seen, he’ll keep his office open. He’ll stay there long enough for my husband to get home and take us all the way back to Glen Burnie before leaving.” Notably, some parents with small children seem especially grateful for the easy access they have to their child’s pediatrician, including staying open later some nights.

Access to Doctors – Urgent Care

In contrast to preventive care, urgent care is care that is required when children are sick. Children who have an acute problem such as an ear infection, the flu or a high fever that is not improving on its own should be able to see a provider for an urgent care visit within 24 to 48 hours. The ability to get their child in to see a doctor under such circumstances is especially important to these parents. Parents are generally pleased with their ability to access urgent care in a timely manner. In fact, according to a few parents, this is an overriding measure of their satisfaction with HealthChoice. When asked if the program was working well for her family, one mother in Baltimore responds, “It depends on if I have to call for an emergency, how soon I can get him there, or how soon they give me an appointment...And usually they’ll just say bring him in.”

When he’s sick, he gets in there right away. But if it’s just checkups, [they say] “Oh well, he can wait a little while.”

Parent, Baltimore Suburbs

As is the case with accessing routine preventive care, most parents are resigned to having to sit and wait in the doctor’s office if they call for a same day appointment. “They give you an appointment time, but if I call or if she’s having problem with her asthma, I need to bring her in, it could be 9:00 in the morning, ‘I can’t give you an appointment until 3:00.’ If you got other patients that come in and this is the only doctor here, then I have to wait until she’s done with these patients. So I have to sit and wait,” says one parent in Baltimore. A parent on the Eastern Shore agrees. “Sometimes they just say come on in and we’ll work you in. You might have to wait an hour. Like last Friday I had to wait an hour and a half, but he was seen.”

Some parents say they do not bother to call their doctor if they feel their child needs urgent care. Instead, they take the child directly to the doctor’s office during office hours, knowing that eventually they will be seen. A parent in Baltimore adds that her child’s primary care provider will make an effort to get them in that day, albeit if it is warranted. “If I see the triage [nurse] and they feel it is important enough to see the doctor, I’ll see the doctor. I’ll be last on the list. The last one probably to be seen but they will be seen,” she insists.

A few other parents in the Baltimore suburbs point out that their urgent care options are limited; namely, there is a shortage of doctors available to provide urgent care. According to them, they have only one small clinic, with only a few nurses and one or two doctors, which often results in a lot of waiting. Meanwhile, a few parents say they use the emergency room immediately, not knowing whether or not they have urgent care services available or assuming that they do not. “I don’t have urgent care so we use the emergency room. If the doctor’s office isn’t there then it’s the emergency room. I’d like to have an Urgent Care. I’d rather use that,” says one parent living in the Baltimore suburbs.

Parents in the Baltimore city and Baltimore suburbs groups were relatively more engaged in the discussion concerning use of urgent care facilities, most likely because urgent care after-hours centers typically exist only in urban and suburban areas. Most of these parents say they were able to use a walk-in clinic and still get to see their doctor of choice that day, which is appreciated. “We come in—we just call them, they say come right in,” says one parent in Baltimore.

Telephone Access

Most parents enjoy a high level of access to their child’s doctors via the telephone. Although most are unable to reach their primary care provider directly, their calls are usually returned in a timely manner, if not by the pediatrician then by a nurse. Explains one parent in Baltimore, “The triage nurse would give me a solution right then and there or call me back.” Parents appear satisfied with this interaction. A few other parents have even more access – they are encouraged to call their child’s doctor on the weekends, either at home or on a cell phone, and not only are their calls returned, but the doctor will often come into the office for them or call in prescriptions. One parent talks about how her pediatricians will call her back with test results.

Parents in some areas, however, felt not so fortunate. A few Medicaid parents in Prince George’s/Montgomery County complain how hard it is reach their doctors. “I page her. They leave the pager number on the answering machine and I page her but she never calls back... I just pick him up and take him to the emergency room. If they ask me anything I just tell them, ‘You didn’t return my page and I had to do what I had to,’” says one parent. They also say that there are no extended hours or late night options available to them.

The same is apparently true on the Eastern Shore, where parents are also unable to get through to doctors. Says one parent there, “I’ve had times where Dr. ____ doesn’t even answer the phone or return his calls. Even sometimes when the hospital pages him you can’t get hold of him.” Another parent in

that same group adds that after hours, “You've got to call the hospital and have him paged. Ninety percent of the time they're not even there.”

Specialty Care

HealthChoice MCOs are responsible for providing and managing the full range of children’s health care except for primary mental health services and occupational, physical and speech therapy services (OT/PT/Speech).

Referrals also play an important part in access to specialty care providers. As mentioned earlier, referrals are a frustrating obstacle to many parents on an administrative level. However, an even bigger complaint about referrals is the time patients must wait before seeing the specialists. Parents report having to make appointments months in advance before they can see the referred specialist. One Eastern Shore mother, who needed to get her son to a neurologist, scheduled an appointment in August for a November visit. Parents with children needing immediate care are very concerned about these long delays for specialist care. One parent in Western Maryland told of her son coming down with an unexplainable skin infection but had to wait three months before he could see a dermatologist.

On this level, long wait times for accessing specialists are doubly problematic to many parents because referrals tend to expire before parents can get their child in to see the specialist, as mentioned in the earlier section on referrals. “I know that a lot those referrals have expiration dates so they have to be within, I can think of one right off the top of my head that has to be within 60 days, so you have to have that appointment within those two months,” laments one parent in Baltimore.

Shortage of Doctors – Primary and Specialty Physicians

Many parents complain about the shortage of doctors, both pediatricians and specialists, in both clinic and in private practice settings. Although a few parents in almost all of the groups point out how difficult it is to find a primary care provider, the loudest complaints originate from outside of Baltimore city and Suburban Maryland, encompassing Baltimore’s suburbs, Western and Southern Maryland, and the Eastern Shore. Two issues appear to be causing this shortage, according to parents: 1) doctors are dropping out of their health plans; and 2) their perception that fewer doctors are participating in HealthChoice plans than previously. Explains one parent in Baltimore, “At the one place we go it’s only one pediatrician. One pediatrician at the clinic. All the other physicians have left.” Or in some cases, parents say doctors who accept their plans are not taking on new patients. In the words of one frustrated parent in the Baltimore suburbs, “Finding the doctor is the hard part. You’ve got to find a doctor that’s accepting new patients. And I’ve tried with

A lot of doctors use to cover some of these HMO’s, but they have dropped them in this area.

Parent, Southern Maryland

[MCO F] and [MCO B] and it's a days work to find a doctor that will say, 'Yes. I'll see you.'"

One result of this shortage of doctors is that parents are forced to travel considerable distances to stay within the plan. One parent says she has to drive 60 miles, from Southern Maryland up into the District of Columbia, with her child for her annual physical. Another points out that she feels somewhat cheated by her plan:

When you first look at the brochures that they offer you, when you first read them, it's looking good. They got the eye doctor once a year, the dentist. And all that reads good until you flip [through] your directory and you see these doctors are not in your area. Then it doesn't seem to look so bright.

The same problems are associated with specialty care as well. Parents in the focus groups say their children use a wide array of specialty care, and often on a regular basis. They say their children visit asthma specialists, cardiologists, pulmonologists, audiologists, dermatologists, neurologists, and one or two have seen a urologist and an endocrinologist. Parents, particularly in the rural areas of the Eastern Shore, Western and Southern Maryland bemoan the lack of specialists in their communities and say they must travel long distances to obtain this care. One parent in Southern Maryland expresses the frustration of many parents:

They just don't have enough. When you look for specialists for certain—like a dentist, and a dentist refers you to a specialist, you're going far away, which is what your HMO will cover. Under that specialist you're here and you're going miles away just to get to a specialist also.

A few parents in each group suggest that the reason for this shortage of doctors is because it is no longer profitable for providers to continue dealing with certain plans; essentially, that the doctors are not getting paid enough by the insurance companies. "That is why I heard that the doctors wouldn't take it. It's hard for them to get their money," says one parent on the Eastern Shore. It appears that some doctors are complaining to their patients about Medicaid's low fee schedule. Says one such parent in the Baltimore suburbs, "My doctors just cancelled all Medical Assistance because they're having problems. And they said a lot of other doctors are canceling all Medical Assistance because of issues." Another parent in Prince George's County offers a more detailed explanation:

Because [my child's doctor] says he's been battling with [MCO B] now for over a year and he's receiving less than 20 percent of what he's supposed to be receiving. He was telling me...that it's over \$5,000 just to keep that one office open. He has two different offices. If [MCO B] is not putting the money out, he can't continue to accept the insurance even though he wants to keep us there. So he said he will give us a couple of months to try to choose another HMO so we can still come to him. But he said he wants us to know ahead of time that this is going to happen.

Health Assessments

Parents were also asked about whether or not their child received a health assessment, physical or check-up within a certain period of time after enrolling in their MCO. The MCOs are required to get newly enrolled children in to see their PCP for a health assessments or physical within 3 months of enrollment or receiving their card, unless the child is sick and requires urgent care or the child is under one month old, in which instances the child is required to have a health assessment within two and 30 days, respectively. For healthy children, the health assessment requirement can be waived if the newly enrolled child is assigned to a PCP with whom he/she already has a longstanding relationship, and the provider indicates that the child has already received the requisite preventive care.

As it turns out, the majority of parents are confused by the notion of a “health assessment” provided by their MCO or HealthChoice when they enroll their child in the program. It is unclear to most parents whether they ever received one, let alone received one in accordance with regulations – especially lower income Medicaid enrollees in Baltimore. “Yes, his doctor did do that. Gave him an assessment of especially how he walked,” recalls one parent in Baltimore. Others believe that assessments “stop at a certain age.” A few parents believe their child did, in fact, receive a health assessment from the program and that it involved completing a questionnaire about their child’s health and medical history. It is important to note that most of these children have been enrolled in the program for a number of years and many have remained with the same primary care provider over time.

I’m on “[Physician Group Practice]”. When they first started to give an assessment chart, they test the ears, the sight, then they do certain stuff to see if they’re active, to see if she’s moving or to see if she could hear. Different stuff...The doctor did all that, and the nurse.

Parent, Baltimore

Emergency Room Issues

Parents are generally aware of their MCO’s emergency room policy. Those parents who are unaware are often left with a hefty bill from their emergency room visit, as discussed under administrative issues in a previous section. However, many other parents know they are required to call their primary care provider in advance for authorization before bringing their child in. In addition, at least one parent in each group adds that their child’s condition must be “life threatening” in order for the visit to be covered by their insurance. As a parent in Prince George’s/Montgomery County explains, “The one [policy] that’s supposed to be standard, across the board. You’re supposed to call your primary care physician first unless it’s a life threatening emergency, a severe bleeding or stopping of breathing.”

What I was told from MCO B...you’re supposed to notify your doctor first. Before you carry your child to the emergency room to make sure that it’s not a visit where they can be seen tomorrow, that there is an urgency.

Parent, Prince George/Montgomery County

Despite their knowledge of this policy, parents across groups complain – and often loudly – that they do not agree with it. Having to obtain permission to take their child to the emergency room is time-consuming, insulting to their

own intelligence as parents, and generally seen as an unnecessary hassle according to most parents. One parent on the Eastern Shore asks sarcastically, “If your child is not breathing and you have to call your doctor to say, ‘Hey, my child is not breathing. Can I take him?’” Another mother who deemed her child seriously ill, was told by her insurance company, upon bringing him in, that the visit was “frivolous” on her part.

Parents do not understand how they can be asked to wait on the phone in an emergency situation. Many parents, particularly in Baltimore, complain about the automated system that is currently in place, placing many of them on hold, or asking them to go through somewhat of a maze to reach the appropriate extension. Meanwhile their child is sick or in pain. A parent in Baltimore adds, “I never call because if my child can’t breathe, I don’t have time to sit on the phone and call you.”

A few more parents express annoyance that others, besides themselves and their children’s pediatrician, get to determine whether a visit to the emergency room is necessary; they wonder if nurses are possibly equipped to determine *over the phone* whether or not their child needs emergency care. A parent in Baltimore, who had been denied authorization and told to “call back Monday” by a nurse, recalls, if my child has a 104 fever regardless if that’s the only complaint, I feel as though he should be in the emergency room, not just give him Tylenol every four hours and call for an appointment.”

I only use it when I think that it is serious enough that [a] child is constantly crying and in pain and if I can’t do anything to ease their pain, I make a phone call to the doctor or to the nurse, 24-hour, and I explain the situation and tell them that I am on my way.

Parent, Baltimore

Those who follow ER utilization rules have better experiences. “As long as you get permission before hand, then it’s no problem,” explains one parent living in the Baltimore suburbs. They say their children are seen without any hassle, rarely have any ER-associated billing problems, and in a few cases, have established a friendly rapport with ER nurses. Notably, parents on the Eastern Shore and in Southern Maryland seem both particularly aware of the MCO policies regarding ER visits and are pleased with their ER experiences.

Lastly, rather than abusing or using ER services arbitrarily, a few parents prefer to avoid it altogether. These parents make the argument that the ER is a hassle to use (to drive there, often long distances, then to have to wait to be seen) – why would parents take their children if it was not absolutely necessary? According to an Eastern Shore parent, “Not too many people want to be bothered with having to go to the emergency room anyway. Especially if it’s for a good reason you do what you have to do.” Parents most commonly speak of using the ER when their children suffer from fevers (usually in the 102+ area), as well as asthma attacks, broken bones and ear infections, and any other seemingly serious problem that they themselves cannot diagnose or solve. “When they’re sick enough, [that’s when I use the ER]” says one parent in Baltimore. Notably, parents are also insistent that they are the ones who know best – when their child is “sick enough” that he or she requires the use of an emergency room.

Prescription Drug Coverage and Durable Medical Equipment (DME)

Prescription drug coverage is not a major area of complaint for Health Choice parents – most of the medications their children need and use are covered by their plans. However, some parents wish that their plan’s formulary included everyday items like over-the-counter pain medications and allergy medications, like Claritin and Zyrtec. Another concern of a few parents is the frequently changing drug formulary, which means they cannot keep track of which medications are covered and which are not.

A handful of parents complain that their plans only allow them use of certain pharmacies, which are limited in number. Parents claim these restrictions are in place under “[Physician Group Practice]”, MCO A, and MCO B. One parent in Baltimore recalls not making it to the pharmacy before it closed and being left with no options. “I can’t take it to Wal-Mart, I can’t take it to K-Mart, I can’t take it to Rite Aid because I’m stuck in this medical plan under this plan and no one else accepts this insurance,” she says, in reference to MCO A. Notably, another parent in that same group disagrees, saying under MCO A she had no problems, but that with “[Physician Group Practice]”, “under that, you can not get it filled in any place.” One parent in Western Maryland says she thinks most pharmacies in her area will fill her prescriptions, but that there are pharmacies in Baltimore that will not take her MCO A card.

Well, I have a problem with it because I can’t go to a Rite Aid or a Giant or anything. I have to go to my clinic to get his medication always. That’s a problem for me. Because the clinic is all the way across town. The doctor is here and I have to go all the way across town to get the prescription.

Parent, Baltimore

Under the state’s Fee-for-service Medicaid program, and in all or most HealthChoice MCOs, pharmacists are required to fill prescriptions with generic drugs unless otherwise specified or approved. For some parents, these policies are problematic, as a few complain that their pharmacists fill generic prescriptions first, which they report not only do not work as well, but are not what the doctor ordered in the first place. In the words of one parent in Baltimore:

They are going to fill a generic first before they do a name brand...a pharmacist will automatically fill it in a generic. If he doesn’t have it in a generic then he will proceed to fill it in a name brand. Once you step outside of those boundaries of that name brand is when you run into your problem.

Some believe and subsequently worry that with the generic drug, their children are receiving inferior, less effective medication. “Now the other one that I had, that was one that wouldn’t fill an allergy prescription for—they wanted to fill it with something that really didn’t work as well. That I think is what—it sounds like the same thing. It’s like they want to fill it with something cheaper, but it’s a totally different formula, and it doesn’t always work as well for that person,” says one parent in Southern Maryland. These parents feel they should get “what the doctor ordered,” because, after all, the “doctor knows best.” As one parent on the Eastern Shore explains, “I just

think it should be up to the medical people with the medical background as to what your child needs, not insurance people that may or may not have any medical knowledge.”

In terms of discussion around the use of medical equipment and supplies, asthma equipment – inhalers and nebulizers – and to a lesser extent, diabetic supplies, are the most common required by children, although a few mention random items like glucogen testers and crutches. “My daughter was diagnosed with asthma and they gave her one of those nebulizers and they cover everything. You get refills when you need them . . . They bring it to me. She has a nebulizer at school and she has one at home,” points out one parent in Baltimore.

While most parents say these asthma-related items are covered by their plan, a few disagree. For example, one parent in Western Maryland says her daughter “has a nebulizer because of her asthma and I’ve never had a problem with that. It was just a simple piece of paperwork,” while another parent living in the Baltimore suburbs, tells a somewhat different story: “They sent me my nebulizer, which was great. But nobody would send me the extra tubing and face masks and, as you know, germs grow inside the tubing and if you don’t replace them you’re just making your child sicker...The doctor said you have to go buy it yourself.”

One parent living in the Baltimore suburbs recounts the struggle she faced trying to get her child his Epi pens (hypodermic needles filled with epinephrine used to combat allergic reactions):

I’ve had the Epi pens problems. They only wanted to give me two because they are \$50 apiece. And, they expire so quickly... But when she goes to school she has to keep them one on her. The nurse wants to have one in her room and I have to have one on me at all times. I have one in my purse now because I’d be the one injecting her when I’m out with her. But I’ve had the insurance company say no. I had to get special permission, actually, is what happened. To get the extra [Epi pens] because they didn’t want to cover them...I had to call up and had to wait for an approval which took three days. It worked out. I was glad they did it because I couldn’t afford them but that’s an issue.

My daughter has glucogen testers. She has to have one in school, one at home and one to travel with. So she has to have three. I had to jump up and down to get them but now there's no problem. They send her three machines each year.

Parent, Baltimore Suburbs

Disagreement arises over diabetic supplies as well. Says one parent living in the Baltimore suburbs, her son’s ‘kit, his monitor, his stick pins, his needles, his insulin, his strips are all paid for,” while a parent there talks of fighting with Medicaid to get “top-rate” machines and supplies for her diabetic child. “For example, they don’t want to pay for BDs, which are the best needles because they are very small. She’s been doing this since she was three years old. They want me to use Monoject, which is a needle that big. It’s the cheapest one. And they don’t care that you’re talking about a child.” These insights suggest that parents are having different experiences when it comes to obtaining durable medical equipment and supplies.

Dental Care

Dental care under HealthChoice is a hot button issue for many of the parents in the focus groups. While happy overall with the health care their children receive, most parents are dissatisfied with their dental care. They complain that too few dentists accept their MCO – or refuse to take new patients – and that the list of participating dentists changes constantly. This is an almost universal concern among parents – be they African American or Caucasian, Medicaid or MCHP enrollees. When this parent from the Baltimore suburbs says with dismay, “The dentist has dropped [MCO F] and I’ve called around and nobody else is accepting [MCO F] anymore...” she echoes a situation that the majority of parents in those areas are currently struggling with.

Why do they have it, then? Why do they have the dental plan...I understand...that it doesn't pay anything. But then why have it? Why offer it, if no one's going to accept it? Why?

Parent, Southern Maryland

Much to parents' dismay, this often forces them to travel long distances to their appointments; others elect not to go at all. A parent in the Baltimore suburbs says, “In my [plan] book there are pediatric dentists but there's only two and they're all the way out in Timonium...I wanted to go out there but I just said, ‘well, it's too far.’” In emergency dental situations, say a few of these parents, they simply take their child to the ER.

Appointments are also a cause for concern; because of so few dentists, there is a back-up of patients waiting to be seen. Parents say they have had to wait anywhere from 2 to 6 months for a routine dentist appointment. Another parent in Southern Maryland warns her fellow participants not to miss their dental appointments, “Because they said it's too many people in the area with HMO's that need dentists and they can't get them. Do not make no appointment and don't keep it, [be]cause they'll never take your child again.”

They need to screen their dentists more carefully. They need to sit down and evaluate these people before they put them on their plans. Just because we can't afford to pay a fortune for dental care doesn't mean we deserve mediocre care.

Parent, Baltimore Suburbs

Parents also complain about the quality of the few dentists that are available – both in terms of actual care and attitude. Many parents assert that their dentists are inadequate and unprofessional – they are often rushing, untidy, sometimes suggesting unnecessary cleanings or treatments, and their staff is often rude. “I just kept saying this is 100% covered. I have to do this,” reasons one parent on the Eastern Shore.

In addition, at least a few parents in each group say that dental coverage is too limited. It is important to note that HealthChoice covers all preventive services and medically necessary restorative, endodontic, surgical, adjunctive and orthodontic services for children. However cosmetic, non-medically necessary orthodontics or braces are not covered. The issue of most concern for parents is braces; since so many children seem to require them, parents are puzzled as to why they have to pay for all if not a percentage of their cost. One parent in Western Maryland believes that the plan “should cover 95% of [the cost] and the parents ought to pay the other five percent if they can, because there are a lot of kids who need braces and they can't get them because of it.” A few parents also agree that the plans are too strict about who qualifies for braces. In the words of one parent in Baltimore:

If I could wave a wand as far as the dental plan is concerned, as far as cosmetics, it would be something that I would like to change. Not everything to me needs to be a medical necessity to get done. I feel as though my son needs braces...He has a terrible over bite... I would have liked to have had that type of procedure done, but with insurance it has to be a medical necessity. He can't swallow. He can't close his mouth.

There are a few parents who are happy with their dental plan; Medicaid parents in Prince George's/Montgomery County, especially those with [MCO D], voice little in the way of complaints on this topic outside of experiencing some difficulty getting appointments. Parents in the MCHP pilot group also had little to complain about, albeit few of them reported using dental services. A few parents in other groups had positive recollections as well, mainly about nurses who called to remind them of upcoming appointments, dentists who provide quality care and, most importantly, children who really like their dentists. In the words of one satisfied parent in the Baltimore suburbs, 'It's important for your kid to be comfortable with the dentist. And when your kids come out and say, 'We really like the dentist. He's cool,' I felt okay with that.' A few of these parents even make recommendations to their fellow participants.

Vision Care

Overall, care from optometrists appears to be satisfactory to parents; however, many have negative comments about the eye glasses covered by the program. Parents complain that the frames their children can obtain through the program are unattractive, one mother even calls them "hideous," cheap, and inferior in quality. One parent in Baltimore says that her son's glasses "broke apart in the first week." Attesting to the unattractiveness of the glasses, another parent in Prince George's/Montgomery County says, "No one likes what Medicaid pays for because they're not very *tres chic*." While parents appreciate that these frames are free, they point out that providing glasses that children will be unwilling to wear is problematic.

The choices that they give you, it's like they make you look like Forest Gump or something like that, and they don't really want to give you something that's worth it. And if you do you might have to pay \$30 more or \$100 more.

Parent, Baltimore

To make matters worse, parents also say they lack choices among frames, 'My son is four years old and they don't let you pick out glasses. They give him these big old plastic things...he knows what he wants to wear. He doesn't want to wear those big old plastic glasses,' says one Eastern Shore parent.

One or two parents in each group also say they have difficulty getting eye doctor appointments for their children. Namely, there are a limited number of eye doctors they can visit. Says one parent in Western Maryland, "It's the same thing as the dental. That there aren't providers who accept the card. I think there's one doctor in the area." Once again, a lack of providers often means traveling long distances for appointments.

Carve-out Services: Mental Health

Awareness and use surrounding mental health services is limited to the handful of parents with children with ADD (or ADHD). Nevertheless, these parents report being very pleased with the care they receive from mental health specialists as well as the coverage HealthChoice affords them. Says one parent in Southern Maryland, “It’s better than private coverage for therapy. Private coverage is like 50%, this covers everything.” Meanwhile, one or two parents who say they were unhappy with the specialist referred to them by their child’s pediatrician were proactive and easily found someone they were satisfied with.

These parents appreciate that their child’s pediatrician is actively involved in overseeing this care, whether that oversight includes simply referrals or actual follow-through. Doctors appear to be referring these children to a variety of sources of mental health care – clinics, the Department of Health, and private doctors. A few parents also report coordination between their child’s school and the Department of Health, most often in the form of sending doctors and therapists to the schools to provide counseling services. The bottom line in this area is clear: parents whose children need mental health care are receiving it.

Some parents do bemoan a lack of choice, however – parents in the Baltimore suburbs speak of having little choice as far as which hospitals or clinics they can use. A few are unhappy with their options. One parent tells the following story:

In my case I had a little problem because they wanted to send my child to class and I didn't want him to go to class. I really did not want him to go. It was some little health program down there on ... Avenue. But I did not want him to go there and they were saying that they were not going to pay for him to go anywhere else. And I said, ‘Well, okay, you don't have to.’ And I enrolled him in the Provider and I paid for it for about six months and then they picked it up and started paying for it.

Notably, mental health services are an issue of great concern on the Eastern Shore, where parents say they recently shut down a facility (Shore Behavioral Health), which severely limits their current options for mental health care. A few of the parents complain about having to scramble to find new therapists and psychiatrists for their children, which was almost impossible given the already limited number available to them. ‘I was fine with Shore Behavioral Health...His therapist was excellent. They broke it up and now I am still looking for a psychiatrist,’ explains one parent there. In contrast, the few parents in Western and Southern Maryland who require these services insist that they do have options; “there are quite a few in the area that accept the plan,” says one parent in Western Maryland.

With mental health in particular, they want you to send them where they want you to send them and you really don't have a choice. I felt I should have had a choice. This is my child, you know?

Parent, Baltimore Suburbs

III. Preventive Care

In addition to administrative and coverage aspects of HealthChoice, parents were asked about preventive care – to define it, to explain its importance, to discuss their use of these services for their enrolled child, and to explain whether or not it was being promoted by the program. The study shows that parents are aware of the importance of preventive care, especially for infants, babies and toddlers, but that not all of them are using preventive care services *regularly*. Like most health care consumers, most parents primarily interact with the health care system when their child is sick or injured – not when healthy.

Insofar as actively promoting preventive care and reminding parents about preventive services is concerned, providers appear to be doing a better job than either HealthChoice or its MCOs. Because most parents do not appear to be using preventive care services of their own initiative, and scheduling routine check-ups is not necessarily ingrained in their routine or lifestyle to any meaningful degree, reminders are an important piece of the puzzle. In fact, although they disagree on the form they should take, many parents agree that reminders are helpful in getting them to take their children for regular doctor's visits.

Knowledge and Use of Services

Most parents recognize the importance of preventive health care. Many define preventive care as annual or regular checkups and, to a lesser degree, immunizations and well-child visits. A parent in Baltimore believes it means “health maintenance.” In her words, “Like she was saying preventive care and if you maintain it then you won’t have a problem.” Most also recognize that regular preventive care helps doctors catch and treat small problems before they become major problems. Like this parent in Baltimore, who says, “If you get regular check-ups – if something is going on, they can get it right then and there. Whereas if you don’t, something may come up, and they could have prevented or they could have treated right then and there.” A few parents mention diet, one for her obese daughter, another for her son with ADD. “Good diet, vitamins, trying to dress your kids up well before they go outside,” suggests a parent living in the Baltimore suburbs.

Parents were asked to complete a brief questionnaire in the focus groups listing recommendations from the Schedule of Preventive Health Care required by the state of Maryland’ EPSDT Program (See Handout 2 in Appendix Two.) Parents were asked to indicate which of these preventive services their children receive. The results provide important insights. It is clear from parents’ responses that their doctors are doing a good job checking

their child's height and weight, as well as filling out the standard "checklist". To a lesser extent, parents report that their children are having objective hearing and vision, as well as blood pressure tests, although this is as expected.

Notably, far fewer parents report that their doctors are performing blood tests on their children during check-ups. In some groups, almost three-quarters of parents say these tests were "definitely not" performed during their child's last physical. However, parents of infants and toddlers are much more likely to have had a blood test taken at their last preventive check-up than parents with older children, which is an important distinction. (Owing to high lead levels in certain areas, regular blood tests should be performed for children under the age of 2.) In particular, parents in Western Maryland, on the Eastern Shore, and in the Baltimore suburbs are the most likely to say these tests were not performed.

Encouragement of Preventive Care

Although most parents in this study use health services only when their child is ill or injured, some appear to be using preventive services reasonably regularly. However, they do not appear to be using them of their own initiative, and scheduling routine check-ups is not necessarily ingrained in their routine or lifestyle to any meaningful degree.

To the extent parents are encouraged to obtain regular well-child care, this encouragement seems to come from providers. Several parents report that their doctor's office sends cards to remind them when their children are due for shots or physicals; some say their doctor's office calls with reminders as well. Most parents, however, say they are reminded on the spot, at their child's appointment, either by the doctor, nurse, or receptionist, like this parent living in the Baltimore suburbs, who says, "I've been pretty fortunate that my doctors [will say], 'Well, Bobby's ten and he's due for his tetanus.'" These parents will generally schedule their child's next appointment right then and there.

My doctor's office calls me to remind of an appointment the next day and I like that, even though I know it is the next day.

Parent, Cambridge

Most parents are also prodded to seek check-ups for their children by schools, which require enrolled children to be up-to-date on their immunizations, and often require physicals for children who play sports. It is also important to note that a number of parents find out which shots are due when they visit the doctor because the child is sick.

In terms of encouragement from MCOs, parents give mixed reviews. It appears that two MCOs (MCO B and MCO D) send out reminders to enrollees about check-ups and immunizations. Parents of children enrolled in all other MCOs say they never receive these kinds of reminders. However, some parents do say they receive pamphlets and other materials from their

MCO about preventive care. This parent in Baltimore says [MCO F's] emphasis on preventive care was a key factor in her switch to that MCO:

That was one of the conditions that really switched me to [MCO F]. [MCO F] in their pamphlet, talked distinctly about preventive care. So whenever my children go they do all of these. They check the height, the urine, the blood, everything... Exactly. It is one of the measures. When they go in, it is all done. I know when they go in their urine will be checked, their blood will be checked.

Nobody is telling us. It's just common knowledge. We just know it.

Parent, Cambridge

The majority of parents, however, insist that their MCO does little or nothing to promote well-child care. Some are surprised that the MCOs do not do more.

It is clear from these groups that reminders are the number one way parents are being encouraged to take their child to the doctor. It is important to note, however, that many if not most parents are confused as to their point of origin – is it the clinic, the doctor, or the MCO sending them reminders? “I don’t know [who sends them],” says one Eastern Shore parent. “Maybe the HMO contacts the physician and says, ‘It’s time for their yearly checkup.’” Some believe reminders are coming from the Health Department.

Furthermore, opinions of such materials are varied and no consensus over their usefulness is reached. Few parents appear to read the MCO newsletter – in fact, some admit to throwing them directly in the trash. But a few parents do say they appreciate receiving something in the mail about preventive care like this parent in the Baltimore suburbs, who says “I think it would help sometimes...it would help me to remember the older children – when they are supposed to have their shots.” Parents are divided over whether telephone reminders are helpful as well.

IV. Stigma

Some parents in the focus groups -- Medical Assistance *and* MCHP parents – believe they have been treated poorly by staff at their clinics and doctor’s offices, and to a much lesser extent the doctors and nurses themselves, because their child receives state assistance. A general comment is that front office staff in doctors’ offices and clinics are the worst offenders and are sometimes disrespectful to HealthChoice enrollees. One parent in Southern Maryland recalls being irritated to the point of tears when a front-desk receptionist refused to let the doctor see her week-old son. “I said he’s sick, he needs to be seen. ‘Well ma’am we can’t help you,’ [she replied].” One parent in Southern Maryland speaking to the pervasiveness of this attitude, “That’s even at the emergency rooms, it’s anywhere, especially the emergency rooms,” she believes.

When I first started out with [MCO B] I met a lot of prejudice because a lot of people...assume because you have Medical Assistance health insurance that your not educated enough to understand quality health care for your children.

Parent, Prince George's/Montgomery County

A few parents, however, offer examples of positive interaction, a willingness to help, and respectful treatment from office staff. One parent of a

child under one year in Baltimore says in reference to the clinic staff, “It is not all of them, it is [just] some of them.” Says one parent on the Eastern Shore, “In fact, sometimes I may be nursing the baby and have a 3-year-old in the car seat and the diaper bag, and the nurses have come right out and helped me carry all of the things back into the room.”

A number of parents feel stigmatized by receiving Medical Assistance, and believe this is why they are treated badly. “I think they think you’re not intelligent. Honestly. I look at them like I’m not a stupid person – don’t talk to me like I am. And they do it on the telephone. And I find that very frustrating,” says one parent living in the Baltimore suburbs. Another parent also from the Baltimore suburbs recalls seeking approval from her pediatrician’s office to go to the emergency room. “Are you sure his fever is high?” “No, it’s 104. It’s not high,” she recalls replying to the nurse sarcastically. Some parents also insist they can feel it in the sighs and mannerisms of staff, as well as in their facial expressions.

Stories of poor treatment by office staff and providers emerged in every focus group. In the words of one parent in Southern Maryland, “I think I was treated better when I paid for my health insurance. I can just feel the difference.” One parent on the Eastern Shore speaks about the receptionists at her pediatrician’s office:

I’ve had several of them get pretty snotty because of the Medical Assistance. I’ve had occasions like you said where I’ve had three of my children sick at one time. She told me I couldn’t do that and then Dr. ____ would tell her, ‘You know, she can’t bring kids at three different times. Put them all in the room. It’s no big deal.’ I’ll call and they kind of get an attitude. ‘It’s not time for their medicine yet.’ Or, ‘He said not to give them the medicine.’ Just smart ways about them. A lot of them are not very friendly.

These parents perceive an attitude on behalf of staff members that because the patients are getting something for free, they can be treated rudely. One parent in Southern Maryland who works in a doctor’s office insists this is more than just paranoia on the part of some Medicaid parents. “I can see some of the girls and staff I work with treat you a little bit different than what the paying person comes in does,” she says.

V. Perceptions of HealthChoice

Parents’ perceptions of HealthChoice are closely tied to their feelings about health insurance generally. Parents in these focus groups have experience with a variety of insurance arrangements, including periods in which their children were uninsured and/or privately insured. Many parents also have experience with Medicaid before the current MCO-based system was adopted. Parents were asked to compare the current MCO-based HealthChoice system with any previous health coverage experience. In each case, parents are

straightforward about which situation they prefer and why. HealthChoice is undoubtedly the preferred coverage of parents who came from a background of no insurance, and many parents who have experience with private insurance give HealthChoice good reviews. Parents familiar with the “red and white card” days of pre-HealthChoice Medicaid point out both pros and cons associated with each.

The following section examines parents experience with and feelings about the various arrangements in more detail.

HealthChoice Compared to Uninsurance

Roughly half of the parents have had periods where their children were uninsured, some of which were short-term while others experienced much longer periods. These parents say they struggled to pay their medical bills during this period, since they had to pay out of their pocket. Although some parents say they were able to pay on a sliding scale at certain health clinics or providers, almost all parents whose children had ever gone without health insurance experienced financial hardship. Indeed, a number of parents say they went into debt over medical bills, which often resulted in damaged credit rating. “My daughter got real sick,” one parent from the Baltimore suburbs states, “[She] had to be taken to the hospital, \$700. And who has it? I mean if you can’t afford the insurance, I couldn’t afford the \$700 either.”

In contrast, several parents choose to wait out their child’s symptoms in order to avoid paying for treatment or medication they cannot afford. While “delaying treatment” is seen to be the “cheapest way” according to some parents, it also means their child usually becomes sicker and may require more costly emergency care. Several other parents are proactive about getting free care for their children during their uninsured periods, seeking out affordable options like free clinics and the health department or employing home care tactics and remedies as alternatives to paying for ER care.

These parents are particularly grateful for the HealthChoice program. Understandably, they stress that their financial concerns over medical bills have all but disappeared, paying out of pocket is no longer an issue, and therefore neither is delaying care for their children. One parent on the Eastern Shore speaks to this point: “It is wonderful and I have even found myself leaving the doctor’s office and going, I have to come up with \$20, \$40, \$60...and then it strikes me, that I don’t have to pay for this. Because when it is an issue for you for so long, and then it is not an issue. I think that it is wonderful.” Another parent in Southern Maryland concurs. “It’s terrible that you have to worry about money over the health of your children...that’s a worry that I’m glad I don’t have now,” she says.

It’s scary. What if they got hurt? What if something serious happened to them? How would you pay for it? How would you do it?...It is so expensive. I don’t understand. These children deserve to have health care.

Parent, Southern Maryland

Although the main thrust of any conversation that compares having no insurance to having HealthChoice revolves around this sense of relief about no longer having to worry about paying for their child's care, a few of these parents note that their children are receiving better quality care. According to One parent in Western Maryland, while uninsured, the care was "not as good as they are getting now."

HealthChoice Compared to Private Employer Based Insurance

For the most part, parents have less experience with private, employer-based insurance for their children. Once again, the main issue is cost; most of those who have experience with private insurance admit paying for this coverage is difficult. In fact, many parents admit it was too expensive – it is like "you were working for insurance," says one parent in Baltimore. Parents use terms like "it was killing me" and "it knocked us out" to describe the financial strain they were under trying to pay the co-pays, deductibles, and other fees associated with private insurance.

Several parents have had very positive experiences with private, employer-sponsored insurance for their children, however. "The benefit with [Commercial Plan] is that it's free. Everything is free. I don't have to pay anything," recalls one parent in Baltimore. While these positive experiences are not commonplace across the research, a few found the co-pays manageable and the overall costs reasonable. It is unclear if this is the result of their children being relatively healthy and therefore requiring little medical attention. One mother in Western Maryland appreciates the universal acceptance of her private insurance stating, "We could go to any hospital, any doctor, anything. And we could get care." Notably, even some parents who bemoan the expense of employer-sponsored insurance acknowledge this last point.

[MCO B] [is better] than my coverage with my job because number one, no co-pay. All the prescriptions are covered, what they do cover. And just not worrying about that deductible because it's quite often that my daughter is admitted.

Parent, Baltimore

Some parents who have experience with private and employer-sponsored insurance – keeping in mind these are few in number – are more divided than those who were uninsured as to which situation is preferable. Once again, the conversation quickly turns to finances. The cost of employer-sponsored insurance – for co-pays and deductibles, as well as ER visits and prescription drugs – was high for many parents, and so they prefer the no-cost HealthChoice system. In fact, this high cost was what motivated most of these parents to enroll in HealthChoice. In this narrow sense, HealthChoice is preferable to private insurance.

Some parents who paid little or nothing for their child's care under their employer's plans feel less positively toward HealthChoice. Many of these parents perceive the treatment they received while privately insured was superior and more personal than under HealthChoice. A few parents in Southern Maryland are particularly convinced of this. "They want to hurry up

and brush you off. You come in to see the child, they figure out something, whatever, and then they send you away. That's the difference I see," says One parent there, while another parent there adds, "I feel that when I would go into the doctor's office, I felt like I was a paying customer and I got better care. I got in quicker. And under [MCO A], it takes me three months to get an appointment to get in, and the nurses treat you lousy. The doctors are really nice, but I got a lot more respect when I had what I call a real insurance card to give them."

Some Baltimore parents whose plans are generally clinic-based are also less likely to praise the current system over private insurance. They point to overcrowded clinics and long waiting periods, in addition to agreeing with parents in Southern Maryland that their child gets less personal service under HealthChoice. "It was personal doctors instead of clinic situations which I liked because I feel like I am just a number in a clinic," says one parent of a child under one year old. Another parent in Baltimore addresses the problem of waiting at clinics:

When you go to "[Physician Group Practice]", your appointment can be at 3:00, but you are not out of there until 5:30 or 6:00...No matter what kind of appointment it is. Then if you walk in, you wait two or three hours. With my insurance on my job, I get the service and it's done and over with. You don't have to wait. It has always been like that. Even if we go to the emergency room, if someone come there and they got Blue Cross and Blue Shield, they are going to see them first. Medical assistance, they can wait.

A few parents in Western Maryland also tend to prefer private insurance to HealthChoice, specifically because there are not enough doctors in their area that accept their current insurance. Shortage of doctors was not a problem when they had private insurance, according to these parents. Says one parent there, her private insurance "was accepted anywhere...Of course it was at a small cost. We had to pay our whatever it was. But now, with [MCO D] you can only go to specific places and you have to have referrals."

Better Now or Better Then? Comparisons to the Days of the "Red and White cards."

Many parents also had experience with pre-MCO Medicaid. A vocal minority insists that the new system has more advantages stemming from the support and coordination managed care and its MCOs provide. Yet, for the most part, parents are hard-pressed to see the advantages of the new system, and perceive the old system to have afforded them a wider choice of providers and more benefits.

Preference for the new system

A few of the parents who experienced the old Medicaid system believe that HealthChoice has more advantages. These parents appreciate the support

their MCO provides; essentially, they embrace the idea of “managed care.” A few parents go as far as to say that the child’s health was *not* managed under the old system. To many, it means that someone else is also looking out for their child’s care, keeping track of their records, appointments and overall health care.

Others also believe the system is better at coordinating their child’s care. “They do know what’s going on with my daughter. I used to go in the hospital and carry a book to tell everybody what was going on because the doctors didn’t know,” insists one parent living in the Baltimore suburbs. A parent in Southern Maryland agrees:

“Now you get more information on the services that they need to have, what they could get. Back then, you had to go to the doctor and ask when should you take them for the ear, nose, and throat doctor. But with the HMO, they tell you what specialists you could see right there in the directory. Where when you just had the red and white card there was no directory to look up if you wanted to change the doctor, if you wanted to see a specialist, you had to go through the physician.”

These opinions around better coordination of care are validated to some extent by two parents, who happen to work in doctor’s offices. Says one, a parent living in Prince George’s/Montgomery County;

I see parents who take their child to this doctor and get their shots. Then they’ll take them to another doctor and get them another set of shots. Then they’ll come in to you and say, ‘My kids haven’t had their shots.’ They don’t know what shots their kids have had and they’ve had two or three of the same shots. Then you have parents who come in and the kids haven’t been to the doctor since the first time they were born. Then you have to give the child six or seven shots at one time. So I think that’s just a better way of managing with the kids and it’s all about the kids.

A Baltimore parent concurs. She recalls seeing many parents coming to her office who failed to keep track of their child’s immunization records and often missed appointments. “It was more of a tracking problem,” she notes. “The parents weren’t being responsible enough to keep them.”

Other parents appreciate that managed care generally means having a regular doctor, which translates into more personal treatment. “You are more seen as a patient than just this person with this card that has to be seen. It is like it is more personal with the doctor,” shares one parent of a child under one year in Baltimore. Granted, not every parent reports enjoying an intimate relationship with their child’s primary care provider, but the quote nevertheless illustrates the importance many parents place on the ease and comfort level that comes with having to see only one, regular doctor.

In addition to more personal treatment, some parents believe the new system allows for greater privacy, whereas the “red and white cards” encouraged feelings of stigma. In the words of one parent of a child under one year in Baltimore, “When a doctor’s name on the card, it is private. It is like you

The plus with the managed care is you have one doctor. My doctor is part of the family. We are personal. I call him at home. He calls me. One doctor is great.

Parent, Baltimore

actually paying for the doctor to see the child with the doctor's name on the card.” Another parent in that same group feels parents receive better treatment now from office and clinic staff than she did under the old system. “I used mine once or twice, but from what I see and have gotten in response from the people at the clinic or whatever, you are more stigmatized by using the red and white cards than you are by using a personal insurance card,” she says.

Lastly, a few parents, from the Eastern Shore and Southern Maryland in particular, recognize and appreciate that it is easier to qualify for coverage under the new system. “It makes it better for the working parent. You can work and your coverage is still there,” says one, while another adds, “That’s probably one way that it’s better; that the income requirement isn’t as hard to meet. You’re able to make more money.”

Preference for the old system

For the most part, parents prefer the old days of Medicaid when they had the “red and white cards” for one overwhelming reason: they enjoyed a wider choice of providers – be they doctors, emergency rooms, or clinics. “You could go anywhere you wanted” is what parents say they valued most about the old system. The following quote from a parent living in the Baltimore suburbs embraces the thoughts of many parents who feel similarly about the old system: “It was better then. You had a wider choice. You weren't stuck with having to go through this person or that person. If I wanted to go across town to see a certain doctor I would go across town and see that doctor. No problem.” In addition, some parents report – and appreciate – that it was a nationwide system; in other words, they could travel out-of-state and know they were covered in the case of an emergency. While this is still the case with HealthChoice, parents do not perceive it as such.

With the red and white card I didn't have to choose the HMO. I went wherever I wanted to. If I was out of state and my son fell out in the street, everyone would take me. I didn't have to call and say, "Can you please... This happened." With the red and white card I could go anywhere I wanted to go.

Parent, Prince George's/Montgomery County

According to these parents, the old system meant less hassle, and much less running around. In addition to not having to choose an MCO, they believe it was generally a much easier system to navigate, mainly because they were not forced to see certain providers. According to one parent on the Eastern Shore:

With these cards you can only go to certain people, whether you like them or not. So if you take your child somewhere and you don't like that person it might be the only person in the organization and you've either got to completely change HMOs to take them... It was less complicated with [MAC] Medical Assistance. If you took your child somewhere and you didn't like the doctor you just got another doctor and you didn't have to go through a big hassle to do it.

A few parents see a connection between the frequency with which they have had to switch plans and/or doctors and the introduction of this new system. One parent in Baltimore believes all the recent switching of doctors in and out

of plans is the main problem with the HealthChoice system, and did not occur before under the old system. “I really am satisfied with the clinic I’m in,” he says, “ [but] that switching doctors or the plan switches...All of a sudden she has [MCO F] with this dentist. All of a sudden, now she doesn’t. If we could keep one doctor, one dentist, fine, it would be great. I would have no problems at all,” he says.

A second item of great frustration resulting from the new system concerns referrals. Parents who say they prefer the days of the “red and white cards” are reportedly annoyed with having to obtain referrals in order to see specialists, a step that was not required under the old system. “Under the red and white card with medical assistance back around then, it was easy to call, just say if you had to go to the allergy clinic, it was easy to call and make an appointment, but now it’s like, when you have to go to different places, they won’t see you... for my children and for myself,” says a parent in Baltimore. Parents are most upset because obtaining the referrals often takes weeks or even months, as noted earlier in the report.

I like the red and white card too because if you want to go to the doctor, you can just go ahead. It would be a whole month before you get a referral with managed care.

Parent, Baltimore

Another main issue which has parents convinced that the old system was better is coverage. Despite the fact that the HealthChoice and old fee-for-service Medicaid benefits packages are identical, parents perceive this not to be the case. According to some, under the old system “everything was paid for.” One parent on the Eastern Shore, who prefers the old system for a variety of reasons, says “It was really simple, I thought. We had the one card, it was red and white and that’s all we did. We didn’t have to go through the referrals and what they would and wouldn’t pay for. I don’t think there was anything they wouldn’t pay for except for braces. That was about it. I think that’s been the same story through the years.” Notably, not only do a few parents on the Eastern Shore point out that they experienced less trouble with prescription drug coverage, but they also add that brand name drugs were covered under the old system (whereas under HealthChoice their options are more limited).

Perception of HealthChoice’s Value-Added Services

While parents report a high level of satisfaction with the HealthChoice program generally, few parents perceive a great deal of value-added by having their children enrolled in managed care. This is not so much a reflection of the program or its benefits, but rather a result of the following three reasons: 1) most parents do not seem to understand the benefits of managed care to their children, and tend to see referrals as a “hassle” rather than an advantage, 2) not all parents are using preventive health services regularly, which are a primary benefit of the MCO system, and 3) with the exception of plans’ nurse help hotlines, the overwhelming majority of parents are unaware of the “extra” services that HealthChoice provides to manage patient’s care and promote good health. The first two factors have already been discussed, so this section will focus on the third factor – the extra services that HealthChoice provides.

Parents are largely unaware of the case management, newsletters and other informational materials, classes and workshops for asthmatics and diabetics, offered by HealthChoice. Parents with children who were enrolled in the old Medicaid system, in particular, fail to recognize that these services are something they did not receive under the old system. It is not so much that parents do not appreciate the provision of these services – because the handful that utilize some of them are grateful – but that most parents are simply unaware that these services exist at all. The nurse’s hotline appears to be the one service parents are both aware and appreciative of.

▪ Case Management

There is almost total misunderstanding surrounding case management. Most parents appear to confuse the concept of an MCO health services case manager with the state’s DSS caseworkers or Medicaid/MCHP caseworkers. Still others appear to confuse this concept with the enrollment brokers or possibly health department staff who helped them enroll and still help them with renewal. A good illustration of the confusion between the concept of MCO case management and DSS case workers is when one parent in Baltimore says, “I think everybody has a case manager ” – in fact, quite a few parents share this belief that everyone is supposed to have one. A parent in Prince George’s/Montgomery County adds, “I think everybody has one, but you probably don’t know.”

Nobody’s ever
contacted me and
asked [about] my
children’s progress.

Parent, Baltimore

It is clear most parents are not familiar with case management in terms of their child’s health care. One parent living in the Baltimore suburbs illustrates this when she said, “No [they do not coordinate services]. They just help you to see whether or not you can be approved for the program,” speaking obviously about an enrollment broker. “I have a case manager only when it’s time for me to send in information about my insurance, like to reapply,” says one parent in Prince George’s/Montgomery County.

The bottom line is that with the exception of one or two parents, most do not benefit from regular contact from a HealthChoice or MCO case manager about their child’s care or the progress of that care. This is especially noticeable in the case of parents whose children have either been seriously ill or needed emergency care. “With my daughter having her brittle bone disease when she was diagnosed when she was six months, I didn’t have a case worker. I had someone tell me or had doctors refer me and say, ‘Hey, you need to go to these meetings for this and do that,’ but I didn’t have one person sit down with me every time one of these things would happen and say, ‘Hey, this is what we’re going to do.’ No,” says one parent living in Prince George’s/Montgomery County.

▪ Newsletters

Most parents appear confused, not only about whether they receive a newsletter but about who is sending it. Few parents recall receiving newsletters from their MCOs, and even fewer take the time to read them. “All that talks about is different classes like breast-feeding classes and rescheduling sibling workshops and stuff like that. It’s stuff that doesn’t even pertain to me,” says one parent on the Eastern Shore. In fact, although few in number, more parents mention receiving newsletters from their clinics and hospitals than from their MCOs directly.

Instead, the main thrust of any discussion around information sent from the MCOs is around reminders for scheduled appointments, often in the form of birthday greetings or postcards, sent from clinics and MCOs (already discussed in the previous section.) A few mention getting coupons in the mail for medications, like cough syrup, and diapers for which they are very grateful. Given the comments – or lack of – from parents on this issue, it is clear that they are either not receiving anything, or do not know they are receiving a newsletter and throw it away.

▪ Classes and Other Services

Only a handful of parents know of or participate in classes or training sessions offered for parents of children suffering from asthma and diabetes. “The doctor did have a training session when they first found out that my daughter had asthma, when they first gave me the nebulizer. The person who brought the nebulizer in instructed me how to use it,” recalls one parent in Baltimore. Meanwhile, one parent on the Eastern Shore wishes she had known about these information sessions before her son’s most recent asthma attack. “If I would have known how to react to it, [then maybe I would not have had to call an ambulance],” she reasons. Notably, knowledge and use of these services is concentrated among parents in Baltimore and its suburbs, and to a few parents in Prince George’s/Montgomery County.

One parent reports having been to a “wellness center” at her hospital, “where they ask for your insurance information. “And in the wintertime, since it’s hard for people to get around, they have a nurse practitioner who comes in three times a week. You can call in the morning if your child has a cold or is sick and the nurse practitioner can write a prescription... They [school] send us home packages every year to sign up for it,” explains one parent living in the Baltimore suburbs. One other parent spoke of attending nutrition counseling for her son at her hospital.

▪ Nurse’s Hotline

My daughter is diabetic and asthmatic and when she became diabetic we went to a class and watched a video. They gave us a coloring book so we could learn what was going on in her body. For her asthma they have a class and they teach her what she can do, what she needs to do, when she needs to do it.

Parent, Baltimore suburbs

As stated earlier, many parents tend to direct emergency care issues to their plan's "nurse's hotline." The majority of parents are aware as well as appreciative of this particular option. Parents share similar, positive experiences and use terms like "helpful" and "good results" when discussing the nurse's hotline. Some parents point out that they can call this hotline after hours, when their clinic is closed, while others like knowing they can reach a nurse in an emergency if they cannot get through to their child's primary care provider.

V. Suggestions for Improvement

An important finding from this research is that overall most parents are satisfied with HealthChoice and the care their children receive through the program. While they would like to see improvements, most aspects of their children's care are going well. Their suggestions for change fall into these categories: administrative improvements, improvements to care and coverage, addressing stigma and poor treatment.

In many cases, where parents across focus groups share common concerns, they also offer similar types of solutions. Parents in certain locations had their own unique concerns and hence their suggestions are not necessarily shared by all. This will be pointed out where applicable.

Administrative Improvements:

- Explain the extra services – value-added benefits, for example, most children are entitled to through HealthChoice.
- Promote preventive services more effectively – parents like the reminders and notes that a few MCOs and many doctors send out.
- Explain the benefits of the MCO system better – i.e., someone managing a child's care, etc.
- Relax requirements in regard to referrals – in some cases, parents would like to just go straight to a specialist.
- Do a better job of explaining MCO rules, particularly relating to ER policy.
- Relax rules around switching MCOs. Do away with the one-year waiting periods so that parents can switch their children more quickly.
- Update lists of doctors and dentists participating in the MCOs more frequently.
- Improve hotline numbers so that parents wait less, receive more follow-through, and are less frustrated when trying to resolve problems.

Improvements to Care and Coverage:

- Recruit more doctors, dentists, and specialists into HealthChoice. This is particularly a problem in rural and smaller communities.
- Reduce waits for children to see specialists – allow them to go outside the plan if the wait is too long.
- Cover the medications that doctors prescribe, not what is necessarily on the formulary.
- Expand coverage to include braces, better eye glass frames, vitamins and other over-the-counter medications, as well as group counseling.
- Expand coverage so that uninsured parents can join the program.

Addressing Stigma and Poor Treatment:

- Additional training for staff, in particular, so that families enrolled in HealthChoice are not treated rudely.

VI. Variation by Race, Income, Health Status of child, Age of Child, and Geography

As stated earlier, this study was designed to discover whether parents' perceptions and experiences differed along lines of race, income level (as indicated by Medicaid eligibility category), or geographic location, as well as age or health status of their children. Findings from the study suggest, however, that little variation exists; in fact, parents sound more similar than dissimilar in their perceptions and experiences vis a vis HealthChoice.

Race

In terms of their perceptions and experiences, Caucasian and African American parents share a similar high regard for the HealthChoice program. They also tend to report similar experiences and frustrations with the program.

Income Level

Similarly, there are no outstanding differences among parents of different income levels; MCHP parents and Medicaid parents agree more than they disagree.

Health Status of Child

Notably, parents of sick children (Group 3, Baltimore City; Group 6, Baltimore suburbs; Group 9, Western Maryland) also express views similar to

those of parents with healthier children. Parents of sicker children voice complaints about the program that echo those of parents of healthier children. Furthermore, parents of sicker children appear to be dealing effectively with their child's health care concerns and many of the issues they may have encountered with HealthChoice and their health plans.

Parents of Newborns

The study also sought to learn the perceptions and experience of parents with children under the age of one (Group 4, Baltimore City) with a focus on newborns. The findings are overwhelmingly positive. Most of these parents are satisfied with the care their newborns received. Enrollment was reportedly easy; it was either automatic (if they themselves were already enrolled in HealthChoice) or most of these parents received help with enrollment from hospital staff. A few parents even point out that someone from their MCO (MCO B, in particular) called to check up on their baby's health after they had left the hospital. They continued to receive assistance with making follow-up appointments and through reminder phone calls. Both general access – scheduling appointments – as well as telephone access to their child's pediatrician seemed relatively high with this group. The only outstanding issue with some of these parents was the amount of time they had to spend waiting in the clinic before seeing a doctor. Furthermore, complaints concerning care and coverage are minimal; parents refer to the care their baby received as “great” and “very thorough”. In fact, almost all of these parents insist that their newborns received all of the requisite immunizations and tests.

Geography

Perhaps the most important difference we discovered was based on geography; most noticeably, rural and urban parents seemed to have different concerns. Already illustrated throughout the report, the following points highlight the main geographical differences.

On an administrative level, eligibility determination concerns are more prevalent among parents in the Baltimore City groups than in any other area, mainly because more of these parents enrolled through the Department of Social Services. While feedback from most parents concerning eligibility determination and renewal is overwhelmingly positive, Baltimore city parents report a more trying, arduous process as a result of using DSS. According to their accounts, eligibility determination was time-consuming, with relatively more paperwork containing unnecessary and intrusive questions, and a few parents even recall receiving rude treatment from workers there.

As for concerns relating to care and coverage, wide variation exists across the state of Maryland. Baltimore city parents appear the most disgruntled when

discussing access to preventive care. Many of these parents receive care in a clinic and report longer waiting times for doctors – both in terms of making appointments and in-office wait times. Meanwhile, parents in the Baltimore suburbs are more likely than others to report a lack of urgent care services despite the availability of urgent care centers in those areas. Although most still say their child is eventually seen the same day, s many report a lengthy waiting time. As a result of this, a few of these parents choose to bypass the urgent care route altogether and take their child immediately to the emergency room.

The issue of most concern among rural parents is the shortage of doctors in the HealthChoice program. This issue is especially troublesome in Western and Southern Maryland and on the Eastern Shore. Most parents in these groups lament not having sufficient choice or availability of doctors – pediatricians or specialists – although lack of dentists poses the largest problem, and to a lesser extent, eye doctors. According to these parents, there are no doctors around or the doctors on the program are not taking new patients. This results in both long waits for appointments and having to travel far distances, both of which appear terribly inconvenient for most of these working parents. The same holds true for mental health services – especially difficult to come by on the Eastern Shore owing to recent closure of a popular facility, Shore Behavioral Health, which has resulted in more limited options for parents there.

Insurance Background

Although not a factor in participant recruitment, differences among the various insurance backgrounds of parents are interesting to note, since they were a factor in shaping parents' perceptions of the program. HealthChoice is undoubtedly the preferred coverage of parents who came from a background of no insurance, mainly because they are no longer struggling with the financial burden of being uninsured, but some also feel less stigmatized on HealthChoice and report they are receiving better quality care. In addition, some parents who have experience with private insurance give HealthChoice good reviews, especially those who had to deal with expensive deductibles and co-pays and other related fees under their private plans. Those parents who experienced few out-of-pocket costs under their private plans are less appreciative of HealthChoice. Some of these parents report receiving better, more personal treatment under their private plans. Lastly, while parents familiar with Medicaid prior to the inception of HealthChoice point out both pros and cons associated with both Medicaid prior to 1997 and the current HealthChoice system, a preference for the old system is evident.

APPENDIX

FOCUS GROUP GUIDE

I. Introduction (10 minutes)

Introduction

Purpose of groups (brief description of project, and how results will be used):

Tonight we are going to be talking about the HealthChoice Program. All of you have children who have been in the program. I want to learn a little bit more about your child[ren]'s experiences with the program -- what's good, what's bad. . .

Introduction of observers, camera people, audio-taping, and assurance of confidentiality

All of the information you share with us tonight is confidential. We only use your first names, and reports do not identify anyone by name. Your participation in the group will in no way affect your enrollment in any government program.

Standard introduction and ground rules for the discussion

Participant introductions

name

children (ages and genders)

II. Health and Insurance Status: Present and Past

1. Where would you say health care falls in terms of your priorities and concerns these days?
2. How are things going for your family in terms of health? How is the health of your children these days?
3. I want to get an idea of everyone's experiences with the different kinds of health insurance and coverage options. Have you had a period when your children were uninsured? [Note number.] For those of you who were uninsured, what was that experience like?

4. Have your children been insured by private insurance you got through an employer?
5. How long has your child been covered by a public program like Medicaid or Medicare?

III. Specifics about HealthChoice Experience

1. Now I want to talk a little more about HealthChoice. What is HealthChoice? What is MCHP? What is Medicaid? Are they different or the same?

I know this is really confusing – it certainly confuses me – so I had the state put together something to explain it. That way, we can all make sure that we are on the same page. [Pass out following:]

What is HealthChoice and How Does It Work?

HealthChoice, which began in 1997, is Maryland's statewide program providing managed care health care coverage for low-income Maryland families. Families whose children are in either 1) Medicaid or 2) MCHP (that is, Maryland's Children's Health Program for Children of working families) are part of the HealthChoice Program

Children who enroll in HealthChoice join a Managed Care Organization (MCO) of their families' choice. Families work with an "Enrollment Broker" to select an MCO. MCOs are sometimes called HMOs. Health care is then provided directly by these MCOs.

Six MCOs currently are part of HealthChoice: United Health Care; Helix Family Choice; Maryland Physicians Care; Priority Partners; Jai Medical Systems; and AMERICAID Community Care.

Once a child is in an MCO, the parent generally selects a regular doctor or Primary Care Provider (PCP) to oversee their medical care.

HealthChoice is responsible for regulating and paying the MCO that your child is in.

2. Is this clear? Any questions?
3. How is the health care program working for your children?

4. Thinking back to when you first signed your children up for the program, what were your expectations? What did you think the program would be like? Is it better or worse than you thought?

III. Specifics about HealthChoice Experiences

Process of enrolling

1. When did you enroll your child(ren) in HealthChoice?
2. How did you hear about it?
3. Tell me a little about the enrollment process, what was it like? Where did you go?
How did it compare with other enrollment processes you've been through? What was the staff like?

IV. HMO's/Pediatricians

A. HMO/s

1. Did you choose your HMO or were you assigned one?
2. How did you decide which one? Did you get the one you chose?
3. What is the difference between the HMO/MCO's?
4. Have you changed MCO's or physicians? Was that easy or difficult?
5. When you first picked your HMO, did you get a packet in the mail? Did you read it? Was it helpful? Did you pick a doctor from the mailing? Did you do this over the phone or by mail?
6. When you originally enrolled, was your child given a "health assessment".
7. Does your HMO:
[Use flip chart with items a -i and columns "Does a good job/Needs improvement"]
 - a. Cover immunizations? Send reminders?
 - b. Have a good dental plan [define good-get priorities] easy to see dentist, appts,
 - c. Prescription Plan [listen for issues with prescription medications] formulary/generic, pharmacy network, charged \$, do DRs just give prescription with no concern for formulary

- d. Provide transportation
- e. Make appointments promptly
- f. Make billing mistakes
- g. Have enough available doctors, specialists
- h. Have caring health care staff
- i. Have an emergency room policy

[for each point determine strengths and weakness and get description of what would make it better]

- 8. What services/medications/specialists do you wish MCO/HMO's covered?

B. Pediatricians/Physicians

- 1. Did you choose your physician/pediatrician or were you assigned one?
- 2. Are you satisfied with the service you get from your pediatrician?
- 3. Have you had to change pediatricians? What was the reason?
- 4. Did you choose your HMO because your physician was in that plan?
- 5. How are you and your children treated by health care providers?
- 6. Can you call your PCP on the phone? Does your pediatrician have evening hours?
- 7. How are you treated by doctors, nurses and other people in medical offices?
- 8. How often do your child(ren) use the program's services?
- 9. Do you ever have to pay for some part of the cost for services? [get details]
- 10. Are routine visits easy to arrange? How about urgent care? Emergency room requests?
- 11. What's it like when you go to the doctor. Turn to Handout 2 and fill out.

Discuss items under not sure and definitely not

- 12. Referrals - what is the process for referrals? Is it easy to get a referral?
- 13. What is your experience when you need to visit a specialist on a regular basis?

V. Preventive Care

1. Does your **HMO** encourage preventive care services? How?
2. How often should you get preventive care services?
3. Does anyone remind you that it's time for your child[ren]'s visit?
Inoculations? When? How? Does it stop at a certain age?
4. Have you ever had to deal with employees in your HMO? What was that experience like?

VI. Services

1. Have you had problems with your health care coverage? What do you do?
2. Where do you go, or what do you do, when you have a problem with your MCO?
3. Who helps you? [Nurse Betty?]
4. Is there an action line/hotline? Have you used it? What was that experience like?
 - a. Whose hotline number did you use [HMO's/HealthChoice] -- where did you find it?
5. Earlier I asked who had experience with having their kids in a private health insurance plan, remind me who said yes. Well, how did this insurance compare with the services you now receive under HealthChoice? For those who had insurance with their companies, how does the insurance you have now compare with the company insurance?
6. For those of you who were in the Medicaid system before, was it better before or is it better now? In what ways?

VII. Renewal - only if time permits

1. Tell me what the renewal process is like. What do you have to do to keep your children in the program? Is the process easy? Hard?
2. How many times have you done this? How often do you have to renew your child(ren)'s membership.

VII. Conclusion

We've talked about a lot of different components of the health care plan and services your child receives, overall, how would describe the quality of medical care your children receive under HealthChoice?

What would make it better?

Do you feel that your PCP does a good job of making sure your children are well?
[For long term enrollees -- Is it better/worse than before?]

**What did I forget to ask you that you were waiting to tell me?

What would you tell the people who set the rules for health care in Maryland?

*** Do you think that most parents know about the state's health care program for children?

THANK AND DISMISS

Handout One

What is HealthChoice and How Does It Work?

HealthChoice, which began in 1997, is Maryland's statewide program providing managed care health care coverage for low-income Maryland families. Families whose children are in either 1) Medicaid or 2) MCHP (that is, Maryland's Children's Health Program for Children of working families) are part of the HealthChoice Program

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Handout Two

At your child's last preventive care CHECK UP

HMO: _____

Age of the child ____.

About how long did this appointment last – that is, about how long did you and you child spend with the doctor in the examining room or in his office? CHECK ONE

- ☐ Under 10 minutes or less
☐ 10 to 15 minutes
☐ More than 15 minutes but less than 30
☐ 30 minutes or more

Did you have time for questions? _____

DURING THE CHECK-UP, DID THE DOCTOR:	Definitely Yes	Not sure	Definitely Not
Fill out a form or check-list asking questions about his or her health and any medical problems they might have experienced since his/her last appointment?			
Check your child's height			
Check your child's weight			
If child is younger than 1 year old, did the doctor measure your child's head circumference			
Give your child an unclothed physical exam			
Give your child a urine test			
Give your child a blood test			
Give a vision test where they are asked to read a wall chart			
Give your child a hearing test where they are given earphones and asked to raise their hands when they hear sounds			
If child older than 3, did the doctor take your child's blood pressure			
IF CHILD OVER 10: Doctor talk to your child alone			